DOCUMENT RESUME

ED 283 354 EC 192 784

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TITLE Special Needs Children Parent Manual. Revised.
INSTITUTION White Mountain Apache Head Start, Whiteriver, AZ.
PUB DATE 86
NOTE 108p.
PUB TYPE Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC05 Plus Postage.
DESCRIPTORS *American Indians; *Disabilities; Educational Diagnosis; Educational Resources; Evaluation Criteria; Evaluation Methods; Handicap Identification; Individualized Education Programs; Mainstreaming; *Parent Rights; *Parent Role; Preschool Education; Reservation American Indians; Special Education; Student Placement; *Student Rights; Teacher Role
IDENTIFIERS Arizona; *Project Head Start; *White Mountain Apache (Tribe)

ABSTRACT

Intended for parents of Head Start children with special needs, this manual explains parental rights and the White Mountain Apache (Arizona) Head Start program for special needs children. Sections discuss and define: mainstreaming; special education; screening, testing, and diagnosis; the role of specialists (pediatrician, speech-language pathologist, audiologist, otolaryngologist, ophthamologist, optometrist, optician, orthopedist, physical therapist, occupational therapist, psychologist, psychiatrist, neurologist); diagnostic criteria; school evaluation; student placement; parents' rights and procedures for appeal; individualized education programs; special concerns on the White Mountain Apache Reservation; parent roles; teacher roles; and resources. (CB)

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WHITE MOUNTAIN APACHE HEAD START

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SPECIAL NEEDS CHILDREN PARENT MANUAL

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DEVELOPED BY:
JUDITH WHITE

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This manual has been compiled for parents of special needs children.

A "Special Needs" child is a child who needs extra attention and help in any area of his/her development, such as: Speech, hearing, vision, behavior, health or learning.

Whenever a Head Start child is referred and receives special services, the parents and that child have special rights.

This manual is to inform parents of those rights and explain how the White Mountain Apache Head Start provides services to children.

REVISED
1986

Butterfly in the Wind

A child is a
butterfly in the wind:
some can fly higher
than others:
But each one flies the
best that it can.
Why compare one
against the other?
Each one is different.
Each one is special.
Each one is beautiful.

"Of such is the kingdom of God."
Luke 18:16

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WHAT DOES MAINSTREAMING MEAN?

"Mainstreaming" means helping people with handicaps live, learn, and work in everyday settings where they will have the greatest opportunity to become as independent as possible. In Head Start programs, mainstreaming is defined as the integration of handicapped children and non-handicapped children in the same classroom. It gives handicapped children the chance to join in the "mainstream of life" by including them in a regular preschool experience, and gives non-handicapped children the opportunity to learn and grow by experiencing the strengths and weaknesses of their handicapped friends.

However, mainstreaming does not simply involve enrolling handicapped children in a program with non-handicapped children. Definite steps must be taken to ensure that handicapped children participate actively and fully in classroom activities.

Mainstreaming is not new to Head Start. Since its beginning, Head Start programs have included handicapped children in classrooms with non-handicapped children. The Economic Opportunity Amendments of 1972 (Public Law 92-424) required that ten percent of the Head Start enrollment in the nation be handicapped children. Two years later, the Headstart Economic Opportunity, and Community Partnership Act of 1974 required that, by fiscal year 1976, not less than ten percent of the total number of enrollment opportunities in Head Start programs in each state be available to handicapped children. And most recently, Public Law 94-142, the Education for All Handicapped Children Act, has mandated that the public schools provide "free, appropriate education" in the "least restrictive setting" for handicapped children from 3 to 21 years of age. Thus, mainstreaming has become an important and well-accepted approach in the education of young handicapped children.

It is the function of Head Start programs to:

> "serve handicapped children in an integrated setting or mainstream environment with other children; provide for the special needs of the handicapped child; and work closely with other agencies and organizations serving handicapped children in order to identify handicapped children and provide the full range of services necessary to meet the child's developmental needs."

Research has shown over and over that the early years of life are critical for learning and growth. It is during this time that children's cognitive, communicative, social, and emotional development can be most influenced. If special needs are recognized and met during these years, handicapped children will have a much better chance of becoming competent and independent adults. Handicapped youngsters who are given the opportunity to play with other children in the Head Start classroom learn more about themselves and how to cope with the give and take of everyday life. This is one of the first steps toward developing independence. By participating in regular preschool settings that are able to provide for special needs, with teachers who know how to adapt teaching techniques and activities, children with special needs will truly have a "head start" in achieving their fullest potential.

BENEFITS OF MAINSTREAMING

There are many benefits to mainstreaming - benefits that affect both handicapped children, as well as their parents and teachers.

MAINSTREAMING HELPS HANDICAPPED CHILDREN

Participating in a mainstream classroom as a welcome member of the class teaches self-reliance to children with special needs and helps them master new skills. For some, it may be the first time in their lives that they are expected to do for themselves the things they are capable of doing. Working and playing with other children encourages handicapped children to strive for greater achievements. Working toward greater achievements helps them develop a healthy and positive self-concept.

A mainstream preschool program can be an especially valuable method for discovering undiagnosed handicaps. Some handicaps don't become evident until after a child enters elementary school and by then much important learning time has been lost. A preschool teacher is able to observe and compare many children of the same age, which makes it easier to spot problems that may signal a handicap. Preschool may therefore be the first chance some children get to receive the services they need. During this time some learning disabilities or potential learning disabilities may be prevented or remedied by early intervention and specific attention to individual children's needs.

MAINSTREAMING HELPS NON-HANDICAPPED CHILDREN

Mainstreaming can help non-handicapped children, too. They learn to accept and be comfortable with individual differences among people. Studies have shown that children's attitude toward handicapped children can become more positive when they have the opportunity to play together regularly. They learn that handicapped children, just like themselves, can do some things better than others. In a mainstream classroom, they have the opportunity to make friends with many different individuals.

MAINSTREAMING HELPS PARENTS

Mainstreaming is also good for the parents of children with special needs. Teachers, other members of the staff, and specialists share the responsibility for teaching a child, the parents come to feel less isolated. They can learn new ways to help their own child. As they watch their child progress and interact with non-handicapped children, parents are helped to think about the child more realistically. They will see that some of the behavior they are concerned about is probably typical of all young children, not just children with handicaps. In these ways, parents come to feel better about their child and themselves.

MAINSTREAMING HELPS TEACHERS

Mainstreaming also has advantages for teachers. Teachers have the chance to make a significant impact on a handicapped child. The techniques developed for working with a child with special needs are just as useful with non-handicapped children who have minor weaknesses in the same areas. In fact, many of the most effective teaching techniques known were first developed for handicapped children. Individualizing programs based on children's specific needs is a basic educational technique that has positive benefits for all children. Finally, working with handicapped children is a chance to broaden both teaching and personal experience.

HOW IS MAINSTREAMING CARRIED OUT?

Mainstreaming can be carried out in a variety of ways. How to mainstream a particular child with a handicap will depend upon the child's strengths, weaknesses, and needs, and will also depend upon the parents, the staff and resources within the community. As you know, every child is an individual with different needs and abilities. This is just as true for children with handicaps: they display a broad range of behavior and abilities.

Some children with special needs may thrive in a full-day program with non-handicapped children. Others will do best in a mainstream environment for only part of the time, attending special classes or other programs for the rest of the day. For still others, mainstreaming may not be the most helpful approach. With few exceptions, children with learning disabilities should be in full-time preschool programs with non-handicapped children. The principle to follow is that children with handicaps should be placed in the "least restrictive environment." This means that the preschool experiences of handicapped children should be as close as possible to those of non-handicapped children, while still meeting the special needs created by their handicaps.

Mainstreaming involves the efforts of many people working as a team - teachers, the child's parents, Head Start staff (in health, education, parent involvement, and social and handicap services), other specialists providing consultant services on a full - or part-time basis, agencies serving handicapped children, and the public schools in the community. The identification, development, and coordination of this team effort is both a challenge and a critical requirement in meeting the needs of a handicapped child.

WHAT IS SPECIAL EDUCATION?

WHAT IS SPECIAL EDUCATION?

Handicapped children may need special education. SPECIAL EDUCATION is a way of teaching what is planned for each handicapped child. It is FREE EDUCATION. A child who needs special education may have teaching by him- or herself or in a small group of children. Special education may use teacher's aides and extra support people such as speech/language pathologists, or physical therapists. Special education teachers may use many different materials and ways of teaching.

SPECIAL EDUCATION CAN BE IN:

- REGULAR CLASSROOM
- SPECIAL CLASSROOMS IN A REGULAR SCHOOL
- SPECIAL SCHOOLS
- PRIVATE SCHOOLS
- HOSPITALS
- INSTITUTIONS
- THE HOME

The laws of the United States and the State of Arizona have steps to follow so handicapped children can have the right education.

It is very important for you, the parents or guardians, to know YOUR RIGHTS and the rights of YOUR CHILD. By knowing, you will make sure that your child will get the education and services he or she needs.

WHAT DO YOU DO IF YOU THINK YOUR CHILD NEEDS SPECIAL ATTENTION?

If your child has not been identified as handicapped but you think he or she has special needs, YOU CAN ASK THE SCHOOL TO EVALUATE YOUR CHILD. The school should pay for the evaluation.

- CALL OR COME INTO YOUR CHILD'S SCHOOL TO REQUEST AN EVALUATION. CONTACT THE HEAD START DIRECTOR OR CHILD SERVICES COORDINATOR.

- ALWAYS KEEP COPIES OF ALL PAPERS. MAKE SURE YOU KNOW THE NAMES OF THE PEOPLE YOU TALK TO AND THOSE WHO SEE YOUR CHILD.

SCREENING, TESTING & DIAÇNOSIS

SCREENING

Screening is a process that identifies children who need specific treatment (for example, eyeglasses or immunization shots) or who need to be referred for a diagnostic evaluation. Screening is therefore an important tool in the early identification of handicapped children.

Screening procedures such as checklists and tests are inexpensive, quick, and easily administered. They give the screener an overview of a child's performance. Teachers, aides, and others need to be trained to use a particular screening procedure correctly. For the screening services that must be provided for every child, see Project Head Start Performance Standards.

Not all children who fail a screening are found to have a problem when they are given a full diagnostic evaluation. This is because the results of screening are not exact, since screening does not assess in depth a child's functioning in a given area. Also, because screening is done in a limited amount of time, the screener may not realize if a certain child is not performing at his or her best at that particular time. For these reasons, a child who is not handicapped may fail a screening and be referred for further evaluation.

On the other hand, some children who pass a screening may, in fact, have a problem that wasn't detected in the screening. If you have a child in your class who has passed the standard screening and you still feel there may be something wrong, do not hesitate to ask an appropriate professional to look at the child more closely.

TESTING

The selection of appropriate tests, their administration, and their interpretation is often a difficult process, requiring a great deal of expertise. Sometimes the precise test needed has simply not yet been developed, and a diagnostician must use the best of what is available and then interpret the results with great caution. Many factors can lead to inappropriate testing or inaccurate test results:

- mistaking one handicap for another
- mistaking cultural differences for handicaps
- mistaking normal physical or mental immaturity for handicaps
- testing a child who is not used to test-like situations
- testing a child when he or she is not feeling well
- testing a child in a language that is not his or her home language
- testing a particular developmental area in a child by requiring a response that involves skills in which the child is handicapped (for example, testing cognitive functioning by requiring a verbal response from a child with an expressive language problem, or a motor response from a child with motor coordination problems).

Even if children are given tests that are appropriate to their age, cultural background, and suspected handicaps - and that are methodologically valid and reliable - test results can be inaccurately interpreted.

To ensure that tests are appropriate to a specific purpose, and that they are administered and interpreted correctly, any screening test that a teacher wants to use should be discussed ahead of time with a trained professional who is knowledgeable about the test. Tests used for diagnostic purposes should be administered and interpreted by specialists trained in the use of the test.

In addition to interviews and histories, your own continuing observation of a child in a variety of situations in your preschool program is an invaluable tool in understanding and helping a child learn. During the preschool years, children experience a great amount of development and change in all areas. This means that ongoing assessment, balanced against overtesting, is needed to provide a more accurate picture of a child's developing skills and functioning. Ongoing assessment can help prevent mislabeling of children.

For additional information on tests, write:

Head Start Test Collection
Educational Testing Service
Princeton, New Jersey 08540

DIAGNOSIS

Diagnosis is a process of gathering information from a variety of sources in order to get a comprehensive picture of a child's functioning and to identify problems areas. The diagnostic process assesses physical and psychological functioning, and learning ability.

A variety of tools should be used in the diagnostic process: interviews (with parents and other adults who know the child well, with the child, with social agency personnel the child has been receiving services from), psychological tests, medical and other reports/tests of physical functioning, and other sources of information about the child. The tests that are used in the diagnostic process take an in-depth look at a child's skills in particular developmental areas. In Project Head Start, diagnosis is to be conducted by an interdisciplinary team of specialists (or a professional who is qualified to diagnose the specific handicap). The diagnostic process should involve:

1. A categorical diagnosis of a child, using Project Head Start diagnostic criteria, to be used solely for reporting purposes.

2. A functional assessment of a child. The functional assessment is a developmental profile that describes what the child can and cannot currently do and that identifies areas requiring special education and related services.

3. An individualized program plan based upon the functional assessment and developed jointly by the diagnostic team, the parents, and the child's teacher.

4. Ongoing assessment of the child's progress by the teacher, the child's parents, and (as needed) the diagnostic team.

The results of the diagnostic process should inform the teacher and parents as to the child's strengths and weaknesses - and hence the child's needs in terms of further learning. The results of the diagnostic process often do not tell the teacher or parents what they should do to help the child in the identified problem areas. Diagnosticians themselves, depending on their knowledge of classrooms and of specific teaching techniques, may be able to discuss with the teacher and parent specific ways in which they can help the child in the classroom and at home. Often the teacher or parent needs to take the initiative in order to obtain this kind of information from a diagnostician.

WHO ARE THE SPECIALISTS?

WHAT DO THEY DO?

WHO ARE THE SPECIALISTS?
WHAT DO THEY DO?

I. GENERAL CARE

A. Pediatrician

1. A medical doctor who cares for children, ages birth to 21
2. What a Pediatrician does:

- asks parents questions about their child's health and development
- does physical examinations
- observes the child
- asks what the child eats
- asks how the child sleeps
- sends the child to other specialists if the child seems to have special problems

II. SPEECH, HEARING, AND LANGUAGE SPECIALISTS

A. Speech-Language Pathologist

1. A person with specialized University training who:

a. Tests and cares for children and adults who have speech problems

b. Tests and cares for children and adults who do not talk, or who cannot understand language, or who use just a few words.

2. A speech-language pathologist is also known as a speech/language clinician

3. What a speech/language pathologist does:

- talks with parents and the child's teacher about their child's speech and language at home and in school
- talks with children to learn about their speech and language
- tests children's speech
- tests how children understand language
- tests how children use language
- teaches children, usually in one-to-one sessions or in small groups
- helps the child's teacher with ideas for the classroom
- helps the parents with ideas for home

B. Audiologist

1. A person with specialized University training who:

a. Screens hearing

b. Tests for hearing problems

c. Recommends hearing aids

d. Helps decide on the best hearing aid

C. Otolaryngologist

1. A medical doctor who:

a. Diagnoses and cares for problems in the ear, nose, and throat

b. Is also known as an Ear, Nose, and Throat doctor (E.N.T.)

2. What an Otolaryngologist does:

- looks at ears, noses, throats to diagnose and treat any problems
- gives medicine
- does surgery
- works with an audiologist

III. EYE SPECIALISTS

A. Ophthalmologist

1. A medical doctor who:

a. Diagnoses and cares for diseases, injuries, or birth defects of the eyes

2. What an Ophalmologist does:

- looks at eyes using lights, pictures, toys (for children), and other instruments
- prescribes glasses
- prescribes medicine
- does eye surgery

B. Optometrist

1. A person with special training who looks at the eyes to diagnose problems with seeing

2. There are some optometrists who specialize in prescribing low vision aids

3. What an Optometrist does:

- observes visual development
- tests visual functioning
- prescribes glasses
- does visual training
- helps teachers choose classroom materials, the best seating, and the best lighting

C. Optician

1. A person with special training to:

a. Make lenses for glasses

b. Make the frames for glasses

c. Put the lenses into the frames

2. What an Optician does:

- helps pick out frame
- measures the head so the frame fits
- cuts and grinds the lenses
- cuts and grinds contact lens

IV. BONE, MUSCLE AND PHYSICAL DEVELOPMENT SPECIALISTS

A. Orthopedist

1. A medical doctor who:

a. Diagnoses and cares for problems with bones, muscles, and joints

2. What an Orthopedist does:

- sets broken bones
- tells what kind of braces or special shoes a person needs
- tells a physical or occupational therapist what kinds of exercises a person needs to build muscle strength
- does surgery

B. Physical Therapist

1. A person with specialized University training who helps people walk, sit, and move

2. Helps people with wheelchairs, braces, special shoes, and crutches

3. What a Physical Therapist does:

- tests children's muscles and strength
- helps a child walk, crawl, sit, stand
- gives a child exercises to make him or her stronger

C. Occupational Therapist

1. A person with specialized University training who helps people use their hands, learn self-help skills, learn how to play.

2. What an Occupational Therapist does:

- tests how children use their muscles to eat, dress, and use their hands
- teaches children how to feed themselves, dress, use the toilet, and wash
- teaches children how to use their hands
- gives a child exercises to make him or her stronger
- plans job training programs based on each child's abilities
- teaches job skills

V. BRAIN AND BEHAVIOR SPECIALISTS

A. Psychologist

1. A person with specialized University training who observes, tests, and helps children and adults who have behavior problems, problems with learning, school or home problems

2. There are many kinds of psychologists - school psychologists, child psychologists, adult psychologists

3. What a Psychologist does:

- may ask children questions about what they like or dislike about school, about home, about him or herself
- observes children playing alone and with others
- asks parents questions about their child, about any problems at home, about themselves
- observes children with their parents
- gives tests that look at thinking, language and remembering
- plays and talks with children to help them learn
- helps parents and children together
- helps the school with the child's program

B. Psychiatrist

1. A medical doctor who:

a. Diagnoses and helps with behavior and learning problems

b. Diagnoses behavior and learning problems that are caused by problems in the brain

c. There are many kinds of psychiatrists - some only care for children, others only care for adults

2. What a Psychiatrist does:

- gives medicine to help control behavior
- observes children or adults at home or at school
- talks with children or adults about what they like or dislike, home, school, fears, or about themselves

C. Neurologist

1. A medical doctor who:

   a. Tests and cares for problems with the brain

2. What a Neurologist does:

   - does physical examinations
   - looks at how we see, hear, feel, taste, and smell
   - looks at how we move
   - does special tests to look at the brain
   - diagnoses and treats epilepsy and cerebral palsy

DIAGNOSTIC CRITERIA

DIAGNOSTIC CRITERIA FOR REPORTING HANDICAPPED CHILDREN IN HEAD START

BLINDNESS:

A child shall be reported as blind when any one of the following exist: (a) child is sightless or who has such limited vision that he/she must rely on hearing and touch as his/her chief means of learning; (b) a determination of legal blindness in the State of residence has been made; (c) central acuity does not exceed 20/200 in the better eye, with correcting lenses, or whose visual acuity is greater than 20/200, but is accompanied by a limitation in the field of vision such that the widest diameter of the visual field subtends an angle of no greater than 20 degrees.

VISUAL IMPAIRMENT:

A child shall be reported as visually impaired if central acuity, with corrective lenses, does not exceed 20/70 in either eye, but who is not blind; or whose visual acuity is greater than 20/70, but is accompanied by a limitation in the field of vision such that the widest diameter of visual field subtends an angle of no greater than 140 degrees or who suffers any other loss of visual function that will restrict learning processes, e.g., faulty muscular action. Not to be included in this category are persons whose vision with eyeglasses is normal or nearly so.

DEAFNESS:

A child shall be reported as deaf when any one of the following exist: (a) his/her hearing is extremely defective so as to be essentially non-functional for the ordinary purposes of life; (b) hearing loss is greater than 92 decibels (ANSI 1969) in the better ear; (c) legal determination of deafness in the State of residence.

HEARING IMPAIRMENT:

A child shall be reported as hearing impaired when any one of the following exist: (a) the child has slightly to severely defective hearing, as determined by his/her ability to use residual hearing in daily life, sometimes with the use of hearing aid; (b) hearing loss from 26-92 decibels (ANSI 1969) in the better ear.

*MULTIPLE HANDICAPS:

Children will be reported as having multiple handicaps when in addition to their primary or most disabling handicap one or more other handicapping conditions are present.

PHYSICAL HANDICAP (ORTHOPEDIC HANDICAP)

A child shall be reported as crippled or with an orthopedic handicap who has a condition which prohibits or impedes normal development of gross or fine motor abilities. Such functioning is impaired as a result of conditions associated with congenital anomalies, accidents, or diseases; these conditions include for example spina befida, loss of or deformed limbs, burns which cause contractures, cerebral palsy.

SPEECH IMPAIRMENT (COMMUNICATION DISORDER)

A child shall be reported as speech impaired with such identifiable disorders as receptive and/or expressive language impairment, stuttering, chronic voice disorders, and serious articulation problems affecting social, emotional, and/or educational achievement; and speech and language disorders accompanying conditions of hearing loss, cleft palate, cerebral palsy, mental retardation, emotional disturbance, multiple handicapping conditions, and other sensory and health impairments. This category excludes conditions of a transitional nature consequent at the early developmental processes of the child.

HEALTH OR DEVELOPMENTAL IMPAIRMENT

These impairments refer to illnesses of a chronic nature or with prolonged convalescence including, but not limited to, epilepsy, hemophilia, severe asthma, sever cardiac conditions, severe anemia or malnutrition, diabetes, or neurological disorders. This may also include Baby Bottle Tooth Decay.

MENTAL RETARDATION

A child shall be considered mentally retarded who, during the early developmental period, exhibits significant sub-average intellectual functioning accompanied by impairment in adaptive behavior. In any determination of intellectual functioning using standardized tests that lack adequate norms for all racial/ethnic groups at the preschool age, adequate consideration should be given to cultural influences as well as age and developmental level (ie, finding of a low I.Q. is never by itself sufficient to make the diagnosis of mental retardation.)

SERIOUS EMOTIONAL DISTURBANCE

A child shall be considered seriously emotionally disturbed who is identified by professionally qualified personnel (psychologist or psychiatrist) as requiring special services. This definition would include but not be limited to the following conditions: dangerously aggressive towards others, self-destructive, severely withdrawn and non-communicative, hyperactive to the extent that it affects adaptive behavior, severly anxious, depressed or phobic, psychotic or autistic.

SPECIFIC LEARNING DISABILITIES

Children who have a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations. Such disorders include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. This term does not include children who have learning problems which are primarily the result of visual, hearing, or motor handicaps, disadvantage. For preschool children, precursor functions to understanding and using language spoken or written, and computational or reasoning abilities are included.

WHAT I NEED TO KNOW ABOUT SCHOOL EVALUATIONS

WHAT I NEED TO KNOW ABOUT SCHOOL EVALUATIONS?

EVALUATION is also called TESTING or ASSESSMENT. An evaluation looks at how your child:

- USES NUMBERS, COUNTS OBJECT
- REMEMBERS
- UNDERSTANDS AND USES LANGUAGE
- SOLVES PROBLEMS

SOMETIMES, a teacher will ask for a child to be evaluated. If the school wants to evaluate your child, you must be told IN WRITING when the school will evaluate (test) your child. The school must get your written permission. If you do not want your child tested, the school may ask for a due process hearing. (See the Due Process section)

It is helpful to work WITH THE TEACHER if your child is having problems in school. You should be able to observe the class if you schedule a time with the school.

WHAT IS A GOOD EVALUATION?

Make sure your child has a complete physical examination, especially for the first school evaluation. This is important! Some children who are called SLOW LEARNERS really have vision or hearing problems.

The evaluation depends on your child's problem(s). Make sure your child's evaluation is a good one.

THE EVALUATION SHOULD:

- BE MORE THAN ONE TEST
- GIVE YOU MORE INFORMATION THAN JUST A NUMBER CALLED AN INTELLIGENCE QUOTIENT OR I.Q.
- PROVIDE YOU WITH A DESCRIPTION OF YOUR CHILD'S PROBLEM(S)
- TELL YOU WHAT YOUR CHILD CAN DO AND WHAT HE/SHE CANNOT DO
- NOT DISCRIMINATE AGAINST YOUR CHILD ON THE BASIS OF RACE, CULTURE OR DISABILITY
- BE GIVEN IN THE LANGUAGE YOUR CHILD UNDERSTANDS BEST

Tests are important but a good evaluation is more than just tests. A GOOD EVALUATION comes from talking with teachers, parents, and other professionals. A good evaluation also comes from watching your child in the classroom, playing outside, and at home.

You may watch the evaluation. Talk to the people who test your child about your child's behavior and abilities. Tell the school people what your child can and cannot do at home. You know your child best. Your information should be used for your child's school program.

WHAT IF I HAVE QUESTIONS?

Make sure you understand what the tests mean. You have A RIGHT to ask what the tests mean if you do not understand. GET COPIES of the evaluation results to keep at home.

When you have some QUESTIONS or DOUBTS about the school's evaluation:

- PROVIDE THE SCHOOL WITH ANY INFORMATION YOU MIGHT HAVE OR KNOW OF CONCERNING THE CHILD
- ASK FOR MORE INFORMATION OR FOR MORE TESTS

You have the RIGHT to ask for an INDEPENDENT EDUCATIONAL EVALUATION of your child if you disagree with the evaluation done by the school. A licensed and qualified evaluator who is not employed by the school conducts the independent education evaluation. The school may pay. If the school thinks that its own evaluation was correct, the school may ask for a due process hearing to decide who should pay for another evaluation.

If your child is receiving SPECIAL SERVICES, the school should do a new evaluation/or update at least every year. If you think your child has changed, you may ask for a reevaluation at any time.

If an independent evaluation is done, you may put the results in your child's permanent school records. The school must consider the results in planning your child's program.

WHAT SHOULD I KNOW ABOUT THE PLACEMENT PROCESS?

WHAT SHOULD I KNOW ABOUT THE PLACEMENT PROCESS?

Handicapped children have SPECIFIC Rights in the placement process. These rights include:

- THE RIGHT TO RECEIVE A FREE APPROPRIATE EDUCATION WITH NONHANDICAPPED CHILDREN.
- THE RIGHT TO BE EDUCATED IN REGULAR CLASSROOMS UNLESS EDUCATION CANNOT BE ACHIEVED THERE EVEN WITH SPECIAL AIDS AND SERVICES.
- THE RIGHT TO A PLACEMENT BASED ON AN INDIVIDUALIZED EDUCATION PROGRAM (I.E.P.)
- THE RIGHT TO A YEARLY REVIEW OF PLACEMENT
- THE RIGHT TO BE EDUCATED IN THE SCHOOL THE CHILD WOULD ATTEND IF NOT HANDICAPPED UNLESS THE INDIVIDUALIZED EDUCATION PROGRAM (I.E.P.) REQUIRES ANOTHER ARRANGEMENT.
- THE RIGHT TO PARTICIPATE WITH NONHANDICAPPED CHILDREN DURING MEALS, RECESS, AND TRANSPORTATION.
- THE RIGHT TO A DUE PROCESS HEARING* TO RESOLVE DISAGREEMENTS ABOUT APPROPRIATE PLACEMENTS.

* See special section on due process.

WHAT IS THE LEAST RESTRICTIVE ENVIRONMENT?

The Least Restrictive Environment (L.R.E.) has different meanings for different handicapped students.

For a severely handicapped child, the least restrictive environment might mean going to a public school class instead a classroom in an institution.

For a mildly handicapped student, the least restrictive environment might mean changing FROM an all day special education classroom TO spending part of the day in a special education resource room.

THE KEY TO THE LEAST RESTRICTIVE ENVIRONMENT IS MAKING THE PLACEMENT FIT YOUR CHILD'S NEEDS, NOT TRYING TO MAKE YOUR CHILD FIT THE PLACEMENT.

The BEST CLASSROOM PLACEMENT for your child should be decided by the multidisciplinary team of parents, teachers and others working with your child.

BASED ON YOUR CHILD'S EVALUATION, THE TEAM:

- DEVELOPS AN I.E.P. LISTING YOUR CHILD'S EDUCATIONAL GOALS AND THE SERVICES THAT WILL BE PROVIDED TO HELP THE CHILD MEET THOSE GOALS.
- DECIDES THE PROGRAM AND CLASSROOM SETTING IN WHICH THE SERVICES CAN BE PROVIDED. THE I.E.P. SHOULD STATE HOW MUCH TIME YOUR CHILD WILL SPEND WITH NONHANDICAPPED STUDENTS AND IN WHAT SETTING THE EDUCATIONAL SERVICES WILL BE PROVIDED.

Even if your child needs to be placed in a special class for most of the school day, he/she COULD SPEND SOME TIME with nonhandicapped students.

Your child should only be placed AWAY FROM NONHANDICAPPED CHILDREN if:

- HE/SHE HAS NEEDS THAT CANNOT BE MET IN THE REGULAR SCHOOL ENVIRONMENT.
- HE/SHE IS A BEHAVIOR PROBLEM AND THOSE BEHAVIORS CAN ONLY BE CONTROLLED IN A SEPARATE SETTING.

IF you and the school cannot agree upon the least restrictive environment for your child, either side may ask for a due process hearing to settle the disagreement.

The Least Restrictive Environment DOES MEAN:

- KEEPING HANDICAPPED STUDENTS WITH NONHANDICAPPED STUDENTS AS MUCH AS POSSIBLE.
- PLACING HANDICAPPED STUDENTS IN SCHOOL SETTINGS WHICH HAVE EDUCATIONAL PROGRAMS TO MEET EACH STUDENT'S NEEDS.

PARENTS' RIGHTS AND PROCEDURES FOR APPEAL

WHITE MOUNTAIN APACHE HEAD START

PARENTS' RIGHTS AND PROCEDURES FOR APPEAL

The following rights are assured you as parents/guardians when an evaluation of your child is to be conducted by the special services of the Head Start Program:

I. YOU HAVE THE RIGHT TO:

A. Be given written notice requesting consent to plan an evaluation of your child.

B. Give written permission for the proposed evaluation.

C. Give written consent for release of confidential information to be used during the evaluation process.

D. Have an individual child evaluation completed within 35 school days (Public Law 94-142) of the date of your consent for your child's evaluation.

E. Be a member of the team conference for your child. As a member of this team, you may present information, including independent evaluations, either in person or in writing. You may attend these team meetings with a representative or appoint a representative to attend.

F. Be informed in writing of the team's recommendations for your child, and to participate in the development of an individualized Education Program (IEP) for your child.

G. Give or deny written consent for any special education placement for your child.

II. IF YOU DISAGREE WITH THE PLACEMENT DECISION FOR YOUR CHILD, YOU HAVE THE RIGHT TO:

A. An impartial hearing to clarify disagreements concerning the placement decision.

B. Be present at or send representatives to the hearing to present evidence, and confront, question, and compel the attendance of witnesses.

C. Appeal the decision for the placement of the local governing board of the agency (i.e. Community Action Agency, Single Purpose Agency, Educational Agency)

D. Make a further appeal, within 20 calendar days (Public Law 94-142) to the State Superintendent of Public Instruction, whose decision shall be final, unless a party initiates civil legal action.

NOTE: If you do not understand the above summary of the law, please contact the Head Start office for more explanation.

WHAT IS PARENT CONSENT?

When the school wants to make changes in your child's program, you have a RIGHT to accept or reject the proposed change.

THE SCHOOL SHOULD GET WRITTEN PERMISSION:

- TO TEST YOUR CHILD
- TO LABEL YOUR CHILD'S HANDICAP
- TO PLACE YOUR CHILD IN A SPECIAL EDUCATION PROGRAM
- TO WRITE AN INDIVIDUAL EDUCATION PROGRAM (I.E.P.)
- TO RELEASE ANY OF YOUR CHILD'S RECORD TO PEOPLE OTHER THAN SCHOOL PERSONNEL OR LEGALLY AUTHORIZED INDIVIDUALS

According to Public Law 94-142, consent means that:

- YOU HAVE BEEN GIVEN ALL RELEVANT INFORMATION ABOUT THE MATTER FOR WHICH CONSENT IS REQUESTED
- THE INFORMATION IS GIVEN IN YOUR NATIVE LANGUAGE
- YOU UNDERSTAND AND AGREE WITH THE INFORMATION
- YOU GIVE WRITTEN PERMISSION
- YOU UNDERSTAND THAT CONSENT IS VOLUNTARY
- YOU KNOW THAT YOU MAY TAKE AWAY YOUR CONSENT AT ANY TIME

If you DO NOT AGREE to have your child tested, the school has the choice of dropping the matter or asking for a due process hearing.

WHAT IS DUE PROCESS?

DUE PROCESS is a term based on the 14th Amendment to the United States Constitution. DUE PROCESS means that no county, state, or school district can take away certain rights without:

TELLING THE INDIVIDUAL WHAT IT PLANS TO DO (WRITTEN NOTIFICATION).
HOLDING A HEARING (TALKING TO WITNESSES, LOOKING AT DOCUMENTS, HAVING A DECISION MADE BY AN IMPARTIAL HEARING OFFICER).

The EDUCATION FOR ALL HANDICAPPED CHILDREN ACT of 1975, Public Law 94-142, guarantees parents, children and schools the right to due process hearings. This law also guarantees to each handicapped child a free appropriate public education. Either you, or the school district may ask for a due process hearing.

WHAT ARE THE STEPS IN DUE PROCESS?

- TALK WITH YOUR CHILD'S TEACHER, PRINCIPAL AND/OR SPECIAL EDUCATION COORDINATOR. MANY DIFFERENCES CAN BE SETTLED WITHIN THE BUILDING IN WHICH YOUR CHILD IS RECEIVING SERVICES. TALKING WITH SCHOOL PERSONNEL IS ALWAYS THE FIRST STEP TO SOLVING PROBLEMS.
- ASK FOR AN INDIVIDUAL EDUCATION PLAN REVIEW MEETING TO DISCUSS YOUR DISAGREEMENTS.
- ASK THE LOCAL SCHOOL DISTRICT FOR A DUE PROCESS HEARING.
- THE HEARING IS ARRANGED BY THE SCHOOL DISTRICT DIRECTLY RESPONSIBLE FOR EDUCATING YOUR CHILD.

  The school will pay the cost of the hearing. There are no costs for you unless you hire a lawyer or pay individuals to speak on your child's behalf. The school should tell you of any free or low-cost legal services.
- TIME BETWEEN NOTICE OF REQUEST FOR A HEARING AND DECISION OF THE HEARING OFFICER SHOULD BE NO LATER THAN 45 DAYS, UNLESS THE SCHOOL AND YOU AGREE TO A LONGER PERIOD OF TIME.
- THE HEARING IS HELD AT A TIME AGREED UPON BY YOU AND THE SCHOOL.
- YOU DECIDE IF YOUR CHILD WILL ATTEND THE MEETING.
- YOU CAN CHOOSE TO HAVE AN OPEN OR CLOSED HEARING.
- A LAWYER OR INDIVIDUAL WHO HAS SPECIAL KNOWLEDGE OF THE PROBLEMS OF HANDICAPPED CHILDREN MAY ATTEND THE MEETING.

YOU, THE LAWYERS, AND OTHER PERSONS REPRESENTING YOUR CHILD:

- CAN PRESENT FACTS WHICH SUPPORT YOUR CASE.
- CAN QUESTION ANY INFORMATION AT THE HEARING THAT HAS NOT BEEN SHARED AT LEAST 5 DAYS BEFORE THE HEARING.
- WRITTEN FINDINGS OF THE FACTS AND A DECISION FROM THE HEARING, UNLESS YOU AND THE SCHOOL HAVE AGREED TO EXTEND THE TIME.

  You can ask for typed transcript or tape recording of the hearing.
- IF YOU DISAGREE WITH THE DECISION, YOU MAY APPEAL THE LOCAL DECISION BY ASKING FOR ASSISTANCE FROM THE ARIZONA DEPARTMENT OF EDUCATION. YOU WILL RECEIVE A WRITTEN DECISION WITHIN 30 DAYS.
- SUE IN STATE OR FEDERAL COURT.

WHEN IS A DUE PROCESS HEARING APPROPRIATE?

You may request a due process hearing WHEN THERE IS A DISAGREEMENT that cannot be resolved to your satisfaction.

You may ask for a due process hearing when you:

- DO NOT AGREE WITH THE IDENTIFICATION OF YOUR CHILD AS HANDICAPPED
- DO NOT AGREE WITH THE SCHOOL'S TESTING RESULTS
- THINK THE TESTING IS INCOMPLETE
- DO NOT AGREE ON WHO SHOULD PAY THE COST OF AN INDEPENDENT EVALUATION
- DO NOT AGREE WITH YOUR CHILD'S PLACEMENT
- DO NOT AGREE WITH THE TYPE OR AMOUNT OF RELATED SERVICES YOUR CHILD IS RECEIVING
- ARE NOT SATISFIED WITH TRANSPORTATION, SPEECH/LANGUAGE THERAPY AND/OR PHYSICAL THERAPY SERVICES FOR YOUR CHILD
- DISAGREE WITH WHAT THE SCHOOL WANTS TO PUT IN THE INDIVIDUALIZED EDUCATION PROGRAM (I.E.P.)
- DO NOT RECEIVE WRITTEN NOTICE OF THE SCHOOL'S INTENT TO CHANGE YOUR CHILD'S PROGRAM
- DO NOT RECEIVE WRITTEN NOTICE OF THE SCHOOL'S INTENT TO EVALUATE, PLACE, OR EXPEL YOUR CHILD

PUBLIC LAW 94-142

In 1975, Public Law 94-142, EDUCATION FOR ALL HANDICAPPED CHILDREN ACT, became a law of the United States. This law gives parents and children RIGHTS.

THE PURPOSE OF SPECIAL EDUCATION UNDER PUBLIC LAW 94-142 IS TO:

- PROVIDE HANDICAPPED CHILDREN WITH FREE, SPECIAL TEACHING AND SUPPORT SERVICES TO MEET THEIR NEEDS.
- PROTECT THE RIGHTS OF HANDICAPPED CHILDREN AND THEIR PARENTS.
- HELP ARIZONA, THE OTHER STATES, AND LOCAL EDUCATION PROGRAMS TO PROVIDE SPECIAL EDUCATION.

This law from the United States government tells you YOUR RIGHTS and your child's rights.

IN ARIZONA, the law says that each public school must find and give special education to all children who need it between the ages of 5 and 21. If your child is to be educated in a BIA school, he or she may be eligible for help between the ages of 3 and 21.

"WHAT'S AN INDIVIDUAL EDUCATION PROGRAM?"

WHAT IS AN I.E.P.?

I.E.P. stands for INDIVIDUALIZED EDUCATION PROGRAM. THE EDUCATION FOR ALL HANDICAPPED CHILDREN ACT, Public Law 94-142, requires that an I.E.P. be written for each student before the student is placed in a special education program.

THE I.E.P. :

- TELLS WHAT THE STUDENT CAN DO AND WHAT HE/SHE NEEDS TO LEARN
- TELLS WHAT SPECIAL SERVICES THE STUDENT NEEDS
- MUST BE REVIEWED ONCE A YEAR
- MUST BE REWRITTEN AT LEAST ONCE A YEAR AND MORE FREQUENTLY IF IT DOES NOT MEET THE STUDENT'S NEEDS

The I.E.P. Meeting, TEAMING or INTERDISCIPLINARY CONFERENCE is required by law. The meeting gives parents, teachers and administrators a chance:

- TO DISCUSS THE STUDENT'S EVALUATION OR PROGRESS IN SCHOOL
- TO SET GOALS FOR THE COMING YEAR
- TO DETERMINE WHAT SPECIAL SERVICES WILL HELP THE STUDENT REACH THOSE GOALS

CONTENT

THE INDIVIDUAL EDUCATIONAL PLAN MUST INCLUDE:

(1) A STATEMENT OF THE STUDENT'S PRESENT LEVELS OF EDUCATIONAL PERFORMANCE

(2) A STATEMENT OF ANNUAL GOALS OR OBJECTIVES

(3) A STATEMENT OF SHORT-TERM INSTRUCTIONAL OBJECTIVES

(4) A STATEMENT OF THE EDUCATIONAL PROGRAM TO BE PROVIDED TO THE THE STUDENT

(5) A STATEMENT OF OTHER SERVICES OR RESOURCES TO BE PROVIDED TO THE STUDENTS.

(6) A STATEMENT OF THE EXTENT THE STUDENT WILL BE ABLE TO PARTICIPATE IN REGULAR EDUCATIONAL PROGRAMS

(7) A STATEMENT OF THE EXPECTED DATE FOR INITIATION OF SUCH PROGRAMS AND SERVICES

(8) A STATEMENT OF THE ANTICIPATED DURATION OF SUCH PROGRAMS AND SERVICES

(9) A STATEMENT OF EVALUATION PROCEDURES INCLUDING CRITERIA AND SCHEDULE FOR DETERMINING WHETHER INSTRUCTIONAL OBJECTIVES ARE BEING ACHIEVED, ON AT LEAST AN ANNUAL BASIS

WHITE MOUNTAIN APACHE HEAD START

Long Range Objectives

In the area of Gross Motor Development, the children at White Mountain Apache Head Start will:

1) Develop the ability to perform vigorous gross motor activities ie., walk, run, jump, hop, skip, climb, and roll.

2) Develop the ability to control and coordinate muscles in order to: push, pull, catch, throw, pedal.

In the area of Fine Motor Development, the children at White Mountain Apache Head Start will:

1) Develop the ability to control finger movement ie., cutting, pasting, tearing, finger painting, sprinkling, tracing, pinching, picking up small objects.

2) Develop hand-eye coordination such as stacking, nesting, sewing, lacing, weaving, beading, putting into, taking out of, pouring, putting together, folding, stringing.

3) Develop hand manipulative skills such as coloring, cutting, painting, opening and closing (doors, faucets, latches, locks, cartons) and twisting.

4) Develop ability to control mouth, teeth, tongue, lips in order to blow, suck, and lick.

In the area of Self-Help Development, the children at White Mountain Apache Head Start will:

1) Develop the ability to manipulate all types of fasteners such as, buttons, snaps, zippers, buckles, ties.

2) Develop the ability to dress themselves without assistance.

3) Develop the ability to serve themselves unassisted in the following ways: pouring, scooping, passing, spooning, and spreading.

4) Develop eating skills appropriate for three and four year olds such as manipulating utensils, using napkins, holding cups, glasses and milk cartons.

5) Develop the ability to assist in food preparation, setting the table, and cleaning the area.

6) Develop good personal hygiene practices such as toileting, dental hygiene, covering mouth, wiping nose, washing hands and face, and caring for hair.

WHO PARTICIPATES IN AN I.E.P. MEETING?

Public Law 94-142 requires that the following people participate in the I.E.P. meeting:

- A REPRESENTATIVE OF HEAD START (DIRECTOR, CHILD SERVICES COORDINATOR) OTHER THAN THE CHILD'S TEACHER, WHO UNDERSTANDS THE EDUCATION OF HANDICAPPED CHILDREN
- THE CHILD'S TEACHER, AND SOMETIMES MORE THAN ONE TEACHER
- THE CHILD'S PARENT (S) OR GUARDIAN (S)
- THE CHILD, WHERE APPROPRIATE
- OTHER INDIVIDUALS IF THE PARENTS OR SCHOOL ASK FOR THEM. FOR EXAMPLE, A SPEECH PATHOLOGIST WHO WORKS WITH THE CHILD MAY ATTEND, OR A PARENT MAY INVITE A FRIEND OR ADVOCATE TO THE MEETING.

For a handicapped child who has been evaluated (tested) for the FIRST TIME, the school district or public agency must require:

- THAT A MEMBER OF THE EVALUATION (TESTING) TEAM PARTICIPATES IN THE MEETING.

OR

- THAT SOMEONE ATTENDING THE MEETING KNOWS ABOUT THE EVALUATION PROCEDURES USED WITH THE CHILD AND CAN REPORT THE RESULTS OF THE EVALUATION

HOW IS PARENT PARTICIPATION ENCOURAGED?

The school is required to encourage parents to attend the meeting.

The school should:

- RESCHEDULE THE MEETING IF YOU ARE NOT ABLE TO ATTEND AT THE SCHEDULED TIME.
- PROVIDE AN INTERPRETER IF YOU USE SIGN LANGUAGE OR IF YOUR NATIVE LANGUAGE IS OTHER THAN ENGLISH.
- ALLOW YOU TO LOOK AT YOUR CHILD'S SCHOOL RECORDS AT THE FIRST PLACEMENT MEETING OR MEETINGS AFTER THE REEVALUATION IF YOU ASK TO DO THIS.
- EXPLAIN ANYTHING IN THE RECORDS THAT YOU DO NOT UNDERSTAND.
- CONTACT YOU THROUGH INDIVIDUAL CONFERENCES OR TELEPHONE CALLS WHEN YOU CHOOSE NOT TO ATTEND THE MEETING.
- MAKE SEVERAL ATTEMPTS TO INCLUDE IN THE I.E.P. MEETING AND KEEP RECORDS OF THESE ATTEMPTS.

HOW DO I PREPARE FOR AN I.E.P. MEETING?

Teachers and staff take time to prepare for I.E.P. meetings. If parents are to be a part of the team, they should do the same. Here are some things you can do before, during, and after the meeting to be prepared.

BEFORE THE MEETING

THINK ABOUT YOUR CHILD'S NEEDS: If your child already has an I.E.P., look over the old I.E.P. Is it helping your child learn? Are there other things that should be added? Other needed services? Are there areas in which your child needs to be tested? If this is the first I.E.P. meeting, what are your child's strengths and weaknesses? What are ways you think the school can help your child learn?

KNOW YOUR CHILD'S RIGHTS: Get a copy of the Federal Rules and Regulations on P.L. 94-142 and the Arizona Rules and Regulations. Some good sources are:

- LOCAL SCHOOL
- DEPARTMENT OF EDUCATION
- TRIBAL LEGAL SERVICES
- PUBLIC LIBRARY

Read the laws and underline important sections. Know the language used in the law. For example, the school is required to provide an APPROPRIATE education, not the BEST or MOST APPROPRIATE one.

WRITE DOWN WHAT YOU THINK YOUR CHILD NEEDS. Read your statement aloud. This will let everyone know of your concerns. You do not need to write the I.E.P. or tell how your child will be taught. You can state what SERVICES your child needs and what OBJECTIVES your child could be working on. (This manual contains a suggested form for parents' input.)

KEEP A FILE OF YOUR CHILD'S RECORDS: A file will help you keep track of your child's progress and the teaching methods that have proved successful. Include copies of all the I.E.P.'s and evaluations, any progress notes the teacher has sent, and letters to and from the school.

ASK TO SEE THE PROPOSED I.E.P: Many schools prepared a proposed I.E.P. before the meeting. If this is true of your school, you could ask to see the document before the meeting so you will have time to look it over and think about it.

AT THE MEETING

YOU DO NOT NEED TO GO ALONE: Parents frequently feel overwhelmed when faced with a room full of school staff. Remember, you may invite anyone you choose: other parents, friends, relatives, or advocates. You do not need to tell the school ahead of time unless you wish to. You may want someone there to help you in asking for a specific program.

YOU MAY RECORD THE MEETING: It may be difficult to take notes while participating in the discussion. You may tape record the meeting if you wish. You do not need to ask permission. If the school tape records a meeting, they must keep the tape as part of your child's educational records, and you have the right to review it as you do any other record.

ADDRESS PEOPLE BY NAME: If you do not know everyone, you could pass around a sign-up sheet to look at during the meeting.

LISTEN CAREFULLY TO THE DISCUSSION: Listen to the school's ideas; it may change your thinking.

BE READY TO ACCEPT THE SCHOOL'S IDEAS ALONG WITH YOUR OWN, but know which things you are willing to continue to ask for. In any discussion, both sides must accept each others ideas.

REMEMBER YOUR CHILD'S NEEDS: It is important to ask for an education for your child which best meets his/her needs. You are not there to listen to the school's budget problems. Your role is to make sure that your child has an appropriate education, so you need not feel guilty about requesting services to meet your child's needs.

REMEMBER YOUR CHILD'S RIGHTS: If there is a particular service your child needs but the school says it cannot provide it, do not feel like you cannot ask for it. Ask to see the written policy that says it is not permitted. Compare this with P.L. 94-142. Remember that federal laws and regulations must be followed. Laws, rules, or policies of the state or school district are then followed.

IF YOU ARE NOT READY TO SIGN THE I.E.P., DON'T: You do not have to sign your child's I.E.P. if you don't understand it, if you feel you need more time to read it, or if you want to consult with other people. There is no harm in telling the school you would like to think about it for a day or two before you sign. Also, while most I.E.P.'s are written for a full year, you could set a shorter time if you want to evaluate a new program. For instance, you might approve the I.E.P. for a period of three months. If the services are working out well, you can simply extend your approval at the end of that time.

AFTER THE MEETING

The important thing now is to follow your child's progress and participate in your child's school program.

IF THE TEAM DOES NOT REACH AN AGREEMENT, consider ways to reach one. You might want to visit programs that the I.E.P. team suggested for your child. Maybe your opinion will change. You might ask opinions of other people who agree with your position to convince the school to agree with you. Be creative in thinking of ways to solve disagreements.

IF A DISAGREEMENT CANNOT BE SOLVED, either parents or school may request a due process hearing to settle the matter. In the meantime the child's placement may not be changed unless parents and school agree to it.

WHAT SHOULD I KNOW ABOUT SCHOOL RECORDS?

The United States has another law of importance to you:

THE FAMILY EDUCATIONAL RIGHTS AND PRIVACY ACT IS FOR ALL CHILDREN IN PUBLIC ELEMENTARY, MIDDLE, AND HIGH SCHOOLS.

This law gives parents, guardians and older students some rights to educational records.

EDUCATIONAL RECORDS means:

REPORTS, TESTS, AND OTHER MATERIALS WHICH HAVE INFORMATION ABOUT YOUR CHILD. THE SCHOOL KEEPS THE RECORDS.

You have SPECIFIC RIGHTS concerning your child's school records.

You have the RIGHT to ask:

- FOR A LIST OF YOUR CHILD'S EDUCATION RECORDS. THE SCHOOL SHOULD LET YOU LOOK AT THOSE RECORDS WITHIN 45 DAYS. YOU SHOULD BE ABLE TO SEE THE RECORDS BEFORE A PLANNED DUE PROCESS OR I.E.P. MEETING.
- FOR ANOTHER PERSON TO LOOK AT THE RECORDS.
- WHAT THE RECORDS MEAN IF YOU DO NOT UNDERSTAND THEM.
- FOR COPIES TO CHANGE EDUCATIONAL RECORDS IF YOU BELIEVE THAT THE INFORMATION CONTAINED IN THE RECORDS IS NOT CORRECT, NOT TRUTHFUL OR VIOLATES THE PRIVACY OR OTHER RIGHTS OF YOUR CHILD.

RIGHT TO CONFIDENTIALITY

You have the RIGHT to know which staff within the school district can see the records. In the case of a medical emergency, specific information may be given to a person dealing with the emergency.

The school may show your child's records to:

- SCHOOL DISTRICT STAFF WHO NEED TO SEE THEM.
- A NEW SCHOOL WHICH YOUR CHILD IS TO ATTEND.
- THE COMMISSIONER OF EDUCATION.

Before ANYONE ELSE can see the records, YOU SHOULD GIVE APPROVAL.

Your consent (approval) should:

- BE SIGNED AND DATED.
- INCLUDE THE RECORDS TO BE SHARED.
- INCLUDE THE PURPOSE FOR SHARING.
- INCLUDE THE PERSONS WHO HAVE ASKED TO SEE THE RECORDS.

One permission form for sharing is NOT PERMISSIBLE. The school should keep a list of the people who have seen the records.

"WHAT DO I LOOK FOR?"

WHAT DO WE LOOK FOR IN A CHILD WHO IS NOT FEELING WELL?

COLDS: Watery, puffy eyes
Sniffles
Cough
Pale color
Fatigue (tired)
Disinterested in activities around him.

ANEMIA: Too little iron in the blood, usually caused by poor nutrition.

Always pale and listless.
Poor skin tone and color.

(too little sleep, problems at home, emotional disturbances, can also cause lack of vitality.)

CONTAGIOUS DISEASES: (most of which can be prevented by immunization.)

Measles - can result in serious complications
Mumps - swollen jaw, infection of the paratid gland

Whooping Cough - pneumonia is a complication
Tetanus - result of injuries - lockjaw
Polio - paralysis, weakness of muscles
German measles - rash, short duration

The following diseases cannot be prevented by immunization and need prompt medical treatment.

Strep throat
Scarlet Fever
Rheumatic Fever

SKIN CONDITION:

Cold sores, small multiple, itchy blisters around the nose and mouth. If they occur frequently, child should be seen by a doctor.
Impetigo: starts with blisters, becoming crusty sores (around the mouth, nose, ears or hands. Spreads to other parts of the body. Very contagious. Needs medical treatment.
Eczema: troublesome but not contagious. Persistent chapped, dry, red and rough skin patches.
Ringworm: common contagious infection of the scalp, skin and nails. Starts as a rounded, puffy, red patch which spreads outward on the skin. On the scalp there are raised, grayish, scaly patches and loss of hair.
Pediculosis: head lice and nits
Scabies: contagious skin problem. Cause: a tiny parasite, the itch mite, gets between the fingers, on the back of hands, in the armpit, inner elbows and groin. Early signs are small reddish tracks on the skin.

CAUSES OF HANDICAPPING CONDITIONS IN CHILDREN

CAUSE	PREVENTION
I. In Utero	
chromosomal abnormalities	genetic screening when indicated
viral infections	have children immunized - avoid having cats in the home if you are pregnant
drugs	don't take drugs unless ordered by your doctor
toxins, poisons	avoid areas recently crop dusted avoid using insecticides
alcohol	don't drink - - even one drink a day can cause a problem in the baby
smoking	don't smoke while you are pregnant mothers who smoke during pregnancy have small babies
maternal illness	have good prenatal care develop good health care habits
II. At birth	
prematurity mechanical injury lack of oxygen to the brain abnormal delivery excessively long labor postmaturity	good medical care during pregnancy and at birth will give the baby the best possible chance to be normal and healthy
III. After birth	
illness	routine child health care and immunizations
near drowning	use safety precautions when swimming or boating
auto accidents	use seat belts - use car seats for infants and young children
toxins or poisons	keep poisons out of the reach of children avoid using toxic sprays or pesticides around children or where they play
abuse and neglect	provide an environment which is stable - an environment in which children are exposed to normal childhood experiences and in which there is love and security

DENTAL PROBLEMS:

Note malocclusion and refer for care.

Caries, or cavities, should be referred for care, which includes Baby Bottle Tooth Decay.

HANDICAPS AND CHRONIC CONDITIONS:

EPILEPSY: dysfunction of the nervous system. Can occur after injuries. Petit Mal = momentary stare, fluttering eyelids, facial twitching. Grand Mal = brief loss of consciousness and convulsive seizure.
Can be controlled with medication (given regularly)

RHEUMATIC FEVER (can follow Strep. infections)
Polyarthris, fever with swollen painful joints.
Chorea (St. Vitus* dance) muscular weakness, emotional instability and uncoordinated muscle movements.
Carditis. (in 50% of cases), fever, child appears tired and pale. Nose bleeds are frequent. Fast or unusually slow pulse. Rash on trunk or extremities.

HEART CONDITIONS: Congential or acquired defects.
Cyanosis: blue color of skin, fingernails, lips, etc.
Dyspneia: breathing difficulties, on exertion.
Swelling of face or extremities
Poor exercise tolerance.
Fatigue

DIABETES: onset is rapid, if uncontrolled, may cause stunting of growth.
Weight loss
Easily fatigued
Polydipsia, excessive thirst
Polyphagia, excessive hunger
Polyuria, excessive urinating

ASTHMA - usually on an allergic basis, or precipitated by respiratory infections.
Wheezing respiratory
Coughing spells
Complains of tightness in his chest.
Complains of not being able to breathe.
Vigorous physical exertion can precipitate transient bronchospasm and wheezing. This often leads to unnecessary and unfortunate restrictions.

FETAL ALCOHOL SYNDROME:
Retardation of growth
Decreased head size
No cleft or indentation above upper lip
Narrow upper lip
Slow mental development
Feeding problems
Appear thin and malnourished.

A S T H M A

ASTHMA IS A CONDITION WHERE THERE ARE SPASMS OF THE BRONCHIAL TUBES IN THE LUNGS OR SWELLING OF THE MUCOUS MEMBRANES OF THE LUNGS AND/OR THROAT.

WHAT TO DO DURING AN ASTHMATIC ATTACK:

1. ACT CALMLY! YOUR ANXIETY WILL ONLY MAKE THE SITUATION WORSE.
2. ADMINISTER MEDICATION! IF THE CHILD IS A KNOWN ASTHMATIC HIS MEDICATION SHOULD ALWAYS BE KEPT ON HAND. MAKE SURE YOU KNOW THE RIGHT WAY TO GIVE THE MEDICATION. IF THE CHILD HAS NO MEDICATION.
3. SEND FOR MEDICAL HELP! CALL THE PARAMEDICS OR TAKE THE CHILD TO A NEARBY HOSPITAL.
4. KEEP THE CHILD SITTING UP! DO NOT ATTEMPT TO HAVE THE CHILD LIE DOWN. THIS MAKES BREATHING MORE DIFFICULT.
5. OFFER SUPPORT AND COMFORT! HOLD CHILD'S HAND OR RUB HIS BACK AND SHOULDER.

SEIZURES

WHAT TO LOOK FOR:

EXCESSIVE SWALLOWING	DROOPY EYELIDS
LIP SMACKING	EYE TWITCHING
DAZE-LIKE SPELLS	SLURRED SPEECH
STARING SPELLS	TWITCHING OF AN ARM OR LEG
TIGHTENING OF BODY MUSCLES	REPETITIVE HAND MOVEMENTS

WHAT TO DO:

During the seizure: The person may fall, stiffen and make jerking movements. Pale or bluish complexion may result from difficult breathing.

1. Keep calm.
2. Help the person into a lying position.
3. Move him away from hard or sharp objects. move them away from him.
4. Put something soft (coat or similiar substance) under his head.
5. DO NOT FORCE anything in a person's mouth.
6. DO NOT try to restrain the person's bodily movements.

After the seizure: The person will awaken confused and disoriented.

1. Turn the person on one side to allow saliva to drain from the mouth and to keep the air duct open.
2. Do not offer the person any food or drink until fully awake.
3. Remain with the person until fully awake.

A paramedic or ambulance need not be called unless:

1. The person is injured.
2. The person has one seizure after another.
3. The person does not start breathing after the seizure (begin mouth to mouth resuscitation)
4. Person requests ambulance.

During the Seizure: The person may have a glassy stare, not respond or give inappropriate responses to questions; sit, stand or walk about aimlessly; make a lip smacking or chewing motion; make unusual sounds; fidget with clothes; appear to be drunk, drugged or even confused and out of contact with surroundings.

1. Do not try to restrain or stop the person.
2. Remove harmful objects from the person's pathway, or direct the person away from them.
3. Do not aggravate the person.
4. When alone, do not approach the person who appears to be aggressive or angry.

After the seizure: The person may be confused after regaining consciousness and should not be left alone until fully awake.

SPECIAL CONCERNS

ON THE

WHITE MOUNTAIN APACHE RESERVATION

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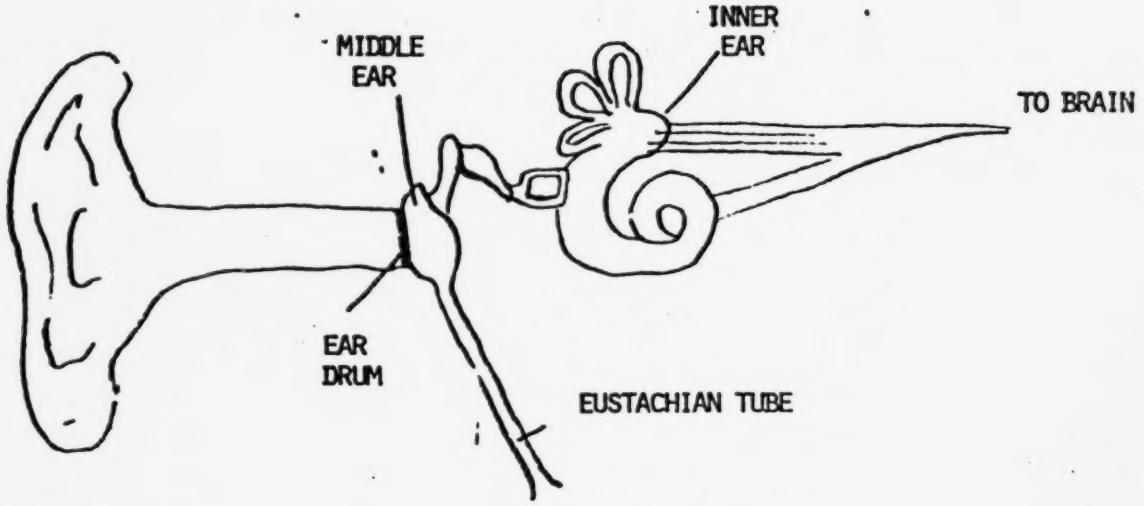
Otitis Media:

For a variety of reasons our Apache children are at risk for middle ear intections, otitis media.

When acute otitis media occurs there is a hearing loss. This is the same time in the child's life that their language is developing. Consequently, many children who have frequent ear infections may also have language delays or handicapps.

Chronic otitis media may also lead to permanent hearing loss which in turn may cause learning delays.



ABOUT THE EAR

FACT

1. DON'T PLACE ANYTHING SMALLER THAN YOUR ELBOW IN YOUR EAR.
2. REPEATED EAR INFECTIONS CAN CAUSE A HEARING LOSS.
3. BEING EXPOSED TO LOUD NOISES FOR ANY LENGTH OF TIME CAN LEAD TO A HEARING LOSS.
4. CHEWING GUM DOES RELIEVE "PLUGGED EARS" AT HIGH ALTITUDES.
5. CHILDREN WITH HEARING LOSSES OFTEN HAVE SPEECH PROBLEMS.

MYTH

1. NOT WEARING A HAT IN THE COLD WEATHER CAUSES EAR INFECTIONS.
2. IF A CHILD HAS A LOT OF WAX IN HIS EAR HE HAS AN INFECTION.
3. HOT BABY OIL WILL CURE EAR PROBLEMS.
4. IF YOU HAVE AN EARACHE, SLEEP ON THAT EAR SO THE INFECTION WON'T GO TO YOUR BRAIN.
5. WEARING BRAIDS AS A CHILD CAUSES YOUR EARS TO STICK OUT.
6. IF YOUR BABY'S EARS STICK OUT, TAPING THEM DOWN WILL MAKE THEM FLAT AGAIN.

DEFINITIONS:

A "deaf" child is a child whose hearing is disabled to the extent that he cannot understand speech through the ear alone, with, or without the use of a hearing aid.

A "hard of hearing" child is a child whose hearing is disabled to the extent that it is difficult, but not impossible to understand speech through the ear alone, with or without a hearing aid.

DEGREE OF HANDICAP	EFFECT ON UNDERSTANDING OF SPEECH	EDUCATIONAL PLACEMENT	FAMILIAR NOISES
NORMAL HEARING 0 to 20dB			10 Faint Whisper 20 Whisper
MILD LOSS 20 to 50dB	May have difficulty hearing faint or distant speech. May have difficulty hearing things at a distance. Should have no speech difficulty due to the hearing loss.	No special placement. May benefit from a hearing aid as loss approaches 30 or 40dB. Attention should be paid to vocabulary development. Needs favorable seating.	30 Whisper 40 Faint Speech very quiet radio 50 Average Conversation; average office noise level
MODERATE LOSS 50 to 70dB	Speech must be loud to be understood. Child will have increasing difficulty in group discussions. Speech is likely to be defective. Child will have difficulties in language usage and comprehension, and vocabulary development. Child will misunderstand speech but may not realize that he is misunderstanding. Will depend on speechreading.	Occasionally requires special class/school placement. Will need special speech, hearing and language assistance. Will need favorable seating in classroom. Will need speechreading training. Individual hearing aid and training.	60 Average Conversation; noisy office 80 Loud Speech very loud radio

DEGREE OF HANDICAP	EFFECT ON UNDERSTANDING OF SPEECH	EDUCATIONAL PLACEMENT	FAMILIAR NOISES
SEVERE LOSS 70 to 90dB	May be able to hear loud voice about one foot from the ear and may be able to identify some environmental sounds. Speech and language will be affected and will not develop spontaneously if the hearing loss is present before 12 months of age unless amplification is provided.	Will need full-time special program for deaf children, with emphasis on all language skills, concept development, lip reading and speech. Part-time placement in regular classes as profitable. Individual hearing aid and auditory training.	80 Loud Speech very loud radio 90 Loudest orchestral music
PROFOUND LOSS 90dB or more	May be able to hear loud sounds but will probably be more aware of vibrations than tonal patterns. Usually relies on vision rather than hearing as the primary sensory channel for communication. Speech and language are defective. Speech and language will not develop spontaneously if the hearing loss is present before 12 months of age.	Will need full-time special program for deaf children, with emphasis on all language skills, concept development, lip reading and speech. Individual hearing aid and auditory training. Part-time in regular classes only for carefully selected children.	90 Loudest orchestral music 100 Subway passing or boiler shop 120 Jet airplane close by

Baby Bottle Tooth Decay:

Baby Bottle Tooth Decay is caused by the prolonged use of the baby bottle. Lying a baby down with a bottle in its mouth often causes problems when the child's teeth are developing.

Also, allowing the child to use a baby bottle past the first year of life may cause tooth decay. When the child continually nurses from a bottle filled with jello water, soda pop, kool-aid, formula, milk or juice there is constant contact with the sugar in these liquids, which in turn may decay the baby's teeth.

Baby teeth may decay to the point where there is also gum disease. Often the child's teeth must be pulled. This often prevents the permanent teeth from coming in properly. Children who have severely decayed teeth are often in a great deal of pain and may later develop speech problems.

You can prevent Baby Bottle Tooth Decay by:

1) Train your child to use a cup by their first birthday

2) Never put soda pop, juice, Kool-aid, or jello water in the bottle.

3) Never put a baby to bed with a bottle.

NURSING BOTTLE MOUTH - QUIZ

Place a (√) check next to the correct answer. Some answers will have more than one (√) check.

1. Sugar should not be added to evaporated milk after age:
   a. 3 months
   b. 6 months
   c. 9 months
   d. 12 months

2. Which of the following liquids do not belong in a baby bottle.
   a. soda pop
   b. milk
   c. baby formula
   d. juice
   e. powdered juice mix
   f. sugar water
   g. plain water

3. Most children are able to drink from a cup no later than:
   a. age 3 months
   b. age 9 months
   c. age one year
   d. age two years

4. Breast feeding usually is/is not a good way to feed your baby.

5. When a child is put to bed with a bottle, which of the following are possible harmful consequences:
   a. crooked teeth
   b. painful toothaches
   c. damage to the adult teeth
   d. a speech problem
   e. serious sickness requiring hospitalization
   f. all of the above

6. A child should be put to bed with a bottle:
   a. at nap time
   b. at night time
   c. never

ANSWERS

(1)-b (2)-a,d,e,f (3)-c (4)-"Is" (5)-f (6)-c

TOODLES MCBLINK

There once was a toothbrush named Toodles McBlink,
Who lived all alone in a holder by the sink.
I'm so lonely wailed poor Toodles
As she cried tears by the oodles.
Nobody love me.
Nobody cares.

I used to be happy.
I used to be glad.
I can remember all the fun I once had.
I used to work with all my might
To keep your teeth shiny and bright.

Now I don't help.
I don't work at all!
I just sit here, alone,
In my holder by the wall.
Such a lonely life wailed poor Toodles
As she cried tears by the oodles.
Nobody love me.
Nobody cares.

Don't let me stay here alone by the sink.
Use me, please use me, begged Toodles McBlink.
I'll help you chase away decay.
Put me to work each and every day.

FETAL ALCOHOL SYNDROME (F.A.S.) FACT SHEET

- We have a high rate of F.A.S. on our Reservation compared to other Reservations.
- It is Not true that only alcoholic women have F.A.S. babies. All pregnant women who drink are at risk.
- The most serious damage that alcohol can do to an unborn baby is cause it to be mentally retarded.
- Besides causing Mental Retardation, Alcohol can cause babies to:
    - Be born small
    - Have an abnormal looking face
    - F.A.S. babies can also have joint (skeletal) problems and heart defects
- A baby who has affected by alcohol may look normal but later may be discovered to have learning difficulties or behavioral problems.
- All of these problems which alcohol causes cannot be corrected later on.
- But...All of these problems can be prevented because F.A.S. is preventable.
- The only sure way for a baby not to be damaged by alcohol is for the mother not to drink alcohol during pregnancy.

Fetal Alcohol Syndrome Prevention Project
U.S. Public Service Hospital
Post Office Box 860
Whiteriver, Arizona 85941

Phone: 338-4911, Ext. 536

FETAL ALCOHOL SYNDROME PREVENTION PROGRAM FACT SHEET:

Symptoms of Fetal Alcohol Syndrome (FAS)

According to Sterling K. Clarren, M.D., FAS expert at the University of Washington, the full fetal alcohol syndrome includes four broad categories outlined in section one. Section two describes each FAS symptom and characteristic in detail.

SECTION I

1) Small size

- Length and weight both before and after birth
- Abnormally small head (microcephaly)
- Children tend to be thin

2) Mental Handicaps

- Mental retardation mild to moderate; irreversible
- Average I.Q. is 60-75, but the range is wide: from as low as 16 to as high as 112 (100 is considered average I.Q.)
- FAS children with the lowest I.Q.'s tend to have the most severe other symptoms as well
- Other central nervous system impairments: hyperactivity, learning disabilities

3) Distinctive Face

- Looks flat in profile
- Small eyes - usually seem to be far apart, are either
- Flat cheeks
- Short, upturned nose in early childhood
- Area between nose and upper lip is elongated; vertical groove dividing this area is flattened or missing
- Narrow upper lip which may give mouth a fish-like shape

4) Possible Problems with Major Organ Systems

- Heart, liver, kidneys, genitals, muscles, bones, and skin

SECTION II

FACE

Nose: Top of nose depressed at ridge between eyes and wider than normal

Eyes: Drooping eyelids; squint; extra fold on inner eyelids; crossed eyes; nearsighted, other eye problems

Ears: Low set; rotated toward back of head; poorly formed; ridge on ear shell

Mouth: Usually open in photographs of FAS babies and children; small teeth; cleft lip/cleft palate; ridges on roof of mouth

Jaw: Blunt in infancy; small chin can remain adnormally small in adolescense or can grow too large in proporation to the rest of the face

Meningitis:

Although the numbers of children diagnosed with H. influenzas meningitis have dropped, it is still a concern because of the possible consequences.

Children who have had meningitis are at risk for hearing loss and possible learning disabilities.

If your child becomes ill and runs a high fever be sure and have them checked as soon as possible by a physician.

"An ounce of prevention is worth a pound of cure!!"

"CLEAN YOUR PLATE OR ELSE!"

The Overweight Child

The notion that "a fat baby is a healthy baby" is familiar to most people. Recent medical research, though, has shown that contrary to popular belief, fat babies are not healthier than babies of normal weight. In fact there is evidence to suggest that early efforts should be to avoid overweight. Overweight is easier to prevent than to cure. People who become fat during childhood find it more difficult to lose weight as adults than those who first become fat as adults. Overweight is a well-known risk factor for many health problems such as diabetes and cardiovascular diseases. We are all aware of the many different ways in which adults try to diet by restricting calorie intake. In working with infants and young children who either have too great a weight for their height or who are gaining weight at too rapid a rate, usually the goal is not to lose weight. Instead, an attempt is made to maintain weight while "catching-up" in height or at least to slow down the rate of weight gain. Consistent with this approach a wide variety of foods should be offered and portion sizes controlled. Some ideas for diet changes to prevent or minimize additional weight gain include:

- -using skim or low fat milk instead of whole milk after one year of age.
- -for preschoolers providing raw vegetables such as carrot and celery sticks and pieces of raw fruits for snacks.
- -for infants eating baby foods, place more emphasis on lower calorie products such as fruits and vegetables and place less emphasis on higher calorie foods such as egg yolks, cereals, mixed dinners, puddings and other desserts.

It is especially important to keep in mind that food should not be pushed on infants and children. Most youngsters have appetites that are just right for their food needs. For instance, at age one many children's appetites naturally decrease because of a slowing in growth rate. By recognizing this fact we will be less inclined to urge them to finish the entire portion in a jar of baby food at one time or to empty the milk bottle. Remember that individual food needs can't necessarily be divided into standard measures of ounces or cups!!

Our discussion on childhood overweight will be continued in the next issue of EGGS. Our focus next time will be on activity level, the other major factor related to weight control.

WHITE HOUSE CONFERENCE CONCEPTS
ON FOOD, NUTRITION, AND HEALTH

I. Nutrition is the process by which food and other substances eaten become you. The food we eat enables us to live, to grow, to keep healthy and well and to get energy for work and play.

II. Food is made up of certain chemical substance called nutrients, that work together and interact with body chemicals to serve the needs of the body.

   a. Each nutrient has specific uses in the body.

   b. For the healthful individual the nutrients by the body are usually available through food.

   c. Many kinds and combinations of food can lead to a well-balanced diet.

   d. No natural food, by itself, has all the nutrients needed for full growth and health.

III. The way a food is handled influences the amount of nutrients in the food, its safety, appearance, taste, and cost; handling means everything that happens to food while it is being grown, processed, stored and prepared for eating.

IV. All persons, throughout life, have need for about the same nutrients, but in varying amounts.

   a. The amounts needed are influenced by age, sex, size, activity, specific conditions of growth and state of health, altered somewhat by environmental stress.

   b. Suggestions for kinds and needed amounts of nutrients are made by scientists who continuously revise the suggestions in the light of the finding of new research.

   c. A daily food guide is helpful in translating the technical information into terms of everyday foods suitable for individuals and families.

V. Food use related to the cultural, social, economic, and psychological aspects of living as well as to the physiological.

   a. Food is culturally defined.

   b. Food selection is an individual act but is usually influenced by social and cultural sanctions.

   c. Food can be chosen so as to fulfill physiological needs and at the same time satisfy social, cultural and physiological wants.

   d. Attitudes toward food are a culmination of many experiences, past and present.

VI. The nutrients, singly and in combinations of chemical substances simulating natural foods, are available in the market; these may vary widely in usefulness, safety of use and economy.

VII. Food plays an important role in the physical and psychological health of a society or a nation just as it does for the individual and the family.

   a. The maintenance of good nutrition for the larger units of society involves many matters of public concern.

   b. The Nutrition knowledge and social consciousness enable citizens to participate intelligently in the adoption of public policy affecting the nutrition of people around the world.

March of Dimes
BIRTH DEFECTS FOUNDATION
1275 Mamaroneck Avenue
White Plains, New York 10605

Public Health Education Information Sheet

CONGENITAL HEART DEFECTS

Some 20,000 infants (one out of every 175) are born with heart defects each year in the United States. The defect may be so small that the baby appears healthy for many years after birth, or so severe that its life is in immediate danger. Congenital heart defects account for about one percent of all heart disease in adults.

What Is A Congenital Heart Defect?

A condition is called congenital if it is present at birth. Heart defects begin in the early part of pregnancy when the heart is forming. Congenital heart defects can affect any of the different parts or functions of the heart.

How Does The Heart Work?

The heart is a muscle that pumps blood to the body. It is divided into four hollow parts called chambers. Within the heart are valves (flaps) that let the blood go forward but keep it from going back. Blood goes from the heart to the lungs where it picks up the oxygen it must have. The bright red blood carrying oxygen goes back to the heart. Then it takes the oxygen through the body by way of arteries (tubes). As it uses up its oxygen it becomes darker, and returns to the heart by way of veins (tubes), where the process starts over again.

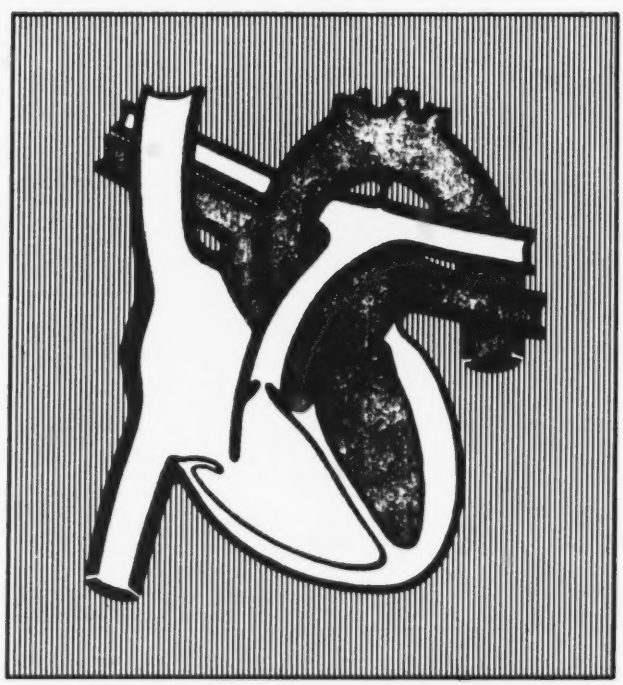


Diagram of a normal heart

How Do Heart Defects Affect A Child?

Some babies are born with a bluish coloring of the skin (cyanosis), especially around the lips, fingers, and toes. This may be normal and soon go away, or it may be the sign of a defect. "Blue babies" have defects that keep their blood from getting enough oxygen. A heart defect also may keep a child from growing and gaining weight normally. He or she may tire easily, feel weak, or have trouble breathing at times. The youngster may squat often because doing that makes it easier to breathe. Symptoms may show up at any age from birth through adulthood.

What Causes Congenital Heart Defects?

In most cases, scientists don't know what makes a baby's heart grow abnormally. Sometimes it is part of a whole pattern of defects that some babies are born with. If a mother has German measles (rubella) during the first three months of pregnancy, her baby's heart may be damaged. (Young women who have never had German measles may be vaccinated against it before they become pregnant.) Heredity may help cause the defect, but how it may isn't known.

How Are Congenital Heart Defects Treated?

Most congenital heart defects can be helped by surgery or medicine. Here are some of the most common defects and their treatment:

- While a baby is in its mother's womb, much of its blood goes through a passageway from one part of the heart to another instead of to the lungs, because the baby gets oxygen from its mother. The passageway should close soon after birth, so the blood can take the normal route from heart to lungs and back. If it doesn't close, blood doesn't flow correctly. A surgeon can close the passageway. In some cases, a new drug makes it close without surgery.
- If the defect is a "hole in the heart" between the two upper or two lower chambers, the blood can't circulate as it should and the heart has to work too hard. A surgeon can close the hole by sewing or patching it. Small holes may heal by themselves.
- Part of the aorta, the large artery that sends blood from the heart to the rest of the body, may be pinched so that the blood can't flow evenly. A surgeon can cut away the pinched part and sew the open ends together.
- Some babies are born with defective heart valves, and blood can't move along smoothly. Surgeons can repair the valves or replace them with man-made ones.
- A combination of heart defects keeps some blood from getting to the lungs for oxygen, and the baby becomes blue and sickly. The baby's brain usually manages to get enough oxygen to prevent mental retardation. Doctors can make temporary repairs until the baby is old enough for final surgery.

Some heart defects can be treated with drugs or mechanical aids such as pacemakers.

Is There A Prenatal Test For Congenital Heart Defects?

Some heart defects can be found through ultrasound, a method of looking at the unborn child using soundwave pictures. In certain heart defects found before birth, drugs can be given to the baby through its mother to help the heart work better. In some cases after the baby is born, the defect may be corrected by surgery. In other cases, where the defective heart can't be treated before birth, doctors can be warned that the defect is present and be ready to give the baby the treatment it needs as soon as it is born.

Can Congenital Heart Defects Be Prevented?

There are no known single, direct methods of prevention. Rubella vaccination and staying away from alcohol and drugs may help.

Genetic counselors can tell parents of affected children roughly what their chances are of having a second child with the same heart defects. Parents who have had an affected child are more likely than others to have a second one with the same defect. But the chances are very small.

What Research On Congenital Heart Defects Is Taking Place?

Scientists funded by the March of Dimes are among many who are trying to learn more about what causes heart defects. Improved treatment and prevention are their goals. Investigators are studying the effects of alcohol and drugs on the development of babies before birth. They are especially looking at how different factors affect the development of the heart. And they are investigating new ways to treat heart defects, before and after birth.

For additional copies contact your local March of Dimes chapter.

March of Dimes
BIRTH DEFECTS FOUNDATION

This information sheet is made possible through contributions to the March of Dimes.

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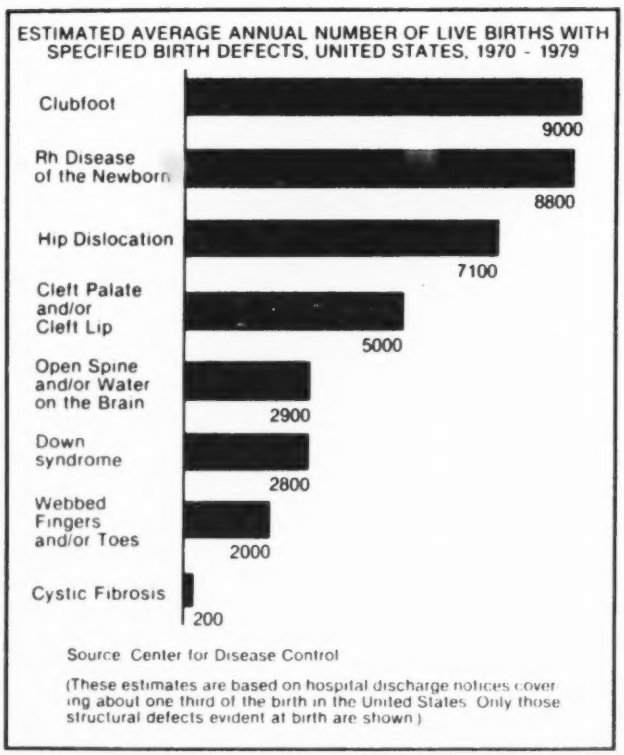
March of Dimes
BIRTH DEFECTS FOUNDATION
1275 Mamaroneck Avenue
White Plains, New York 10605

Public Health Education Information Sheet

CLEFT LIP AND PALATE

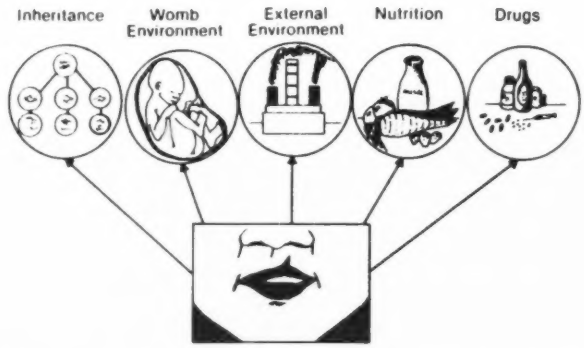
Some 5,000 children (one out of every 700 births) are born with cleft lip or palate in the United States each year. "Cleft" describes a split where parts of the upper lip or palate (roof of the mouth) fail to grow together. Some have only cleft lip, also known as "harelip," while more have only cleft palate. About 40 percent have both cleft lip and palate. The defect appears more often among Orientals and certain tribes of American Indians than among white Americans. It occurs less frequently among black Americans.


ESTIMATED AVERAGE ANNUAL NUMBER OF LIVE BIRTHS WITH SPECIFIED BIRTH DEFECTS, UNITED STATES, 1970 - 1979
Clubfoot
9000
Rh Disease of the Newborn
8800
Hip Dislocation
7100
Cleft Palate and/or Cleft Lip
5000
Open Spine and/or Water on the Brain
2900
Down syndrome
2800
Webbed Fingers and/or Toes
2000
Cystic Fibrosis
200
Source: Center for Disease Control
(These estimates are based on hospital discharge notices covering about one third of the birth in the United States. Only those structural defects evident at birth are shown.)

What causes cleft lip and palate?

There is no one cause for all clefts. Scientists believe that any number of factors such as drugs, disease, heredity, malnutrition, and adverse environment may act on each other to disturb normal growth. Many infants with cleft palate are premature and have other defects.

Heredity appears to play a role in about 25 percent of cases. In the other 75 percent there is no family history of the defect, even among distant relatives. It is known that if both parents are normal and have a child with a cleft, the chances that subsequent babies will have a cleft increase progressively. If either parent has a cleft, there's a four percent chance that their first baby will have a cleft, and the chances increase with each time they have an affected child.



Scientists believe that any number of factors acting on each other may result in cleft palate or cleft lip.

How do clefts affect a baby's face?

Cleft lip may involve only one side of the upper lip or both. The split may be only in the upper lip, or may extend up into the nostril. Usually the split goes through the outer skin, muscles, and inside of the lip. Cleft palate may involve only the soft part of the palate toward the back of the throat, or it may extend forward through the hard palate.

How are cleft lip and palate treated?

Treatment usually combines surgery, speech therapy, dental corrections and psychological help. Depending on the type of cleft and the infant's general condition, corrective surgery can be started within the first few months. It may be a simple stitching together of the separated edges of the lip; or with a cleft palate, several operations may be necessary. Sometimes tissue grafts are needed. Temporary dental splints or plates are used to keep the upper jaws in proper alignment before and between operations. Braces may be needed later because teeth usually grow in crooked and some may remain impacted in the jaw.

What are the special problems related to cleft lip and palate?

Feeding is the first problem to be overcome. Since a split in the roof of the mouth makes it difficult for a baby to suck, food backs up through its nose and may cause choking. Parents are taught to feed the baby in an upright position, in small amounts, using a nipple with a large hole or syringe.

Defective speech is one of the most serious results of cleft palate and, to a lesser extent, cleft lip. Psychological problems may result from speech difficulties and the child's unusual appearance before clefts are repaired, and require a professional counselor's help. Clefts have no relation to mental ability or retardation.

Ear infections are common. Difficulty in swallowing affects air pressure around the inner ear, spreading infection directly through the nose to ear. Frequent or severe ear infections may lead to hearing loss.

Can cleft lip and palate be prevented?

If there is any history of cleft palate or lip in the family, or a history of any other condition of which the cleft is a part, a genetic counselor can determine the chances for passing on the defect. Since certain drugs may influence structural growth, it is important for an obstretrician to know if the pregnant patient is taking such medications as anti-convulsants, sedatives, insulin, etc., or if she is on a special diet. Early and regular prenatal care and good health habits are important for prevention of many birth defects, but cannot guarantee that all babies will be normal.

What research is being done?

Studies have shown that mouth clefts are established by the eighth week of pregnancy. By then, upper jaw and nose tissues have finished growing toward a midline where they fuse to form the palate and upper lip. Because there are so many factors or combinations of factors that may affect this complicated procedure, research takes many paths.

Scientists are studying the effects on facial development of drugs used to treat epilepsy. Children of epileptic mothers taking anti-convulsant drugs have five to 10 times the usual incidence of cleft lip and palate. Investigators are also studying the possibility that the enzyme (activator) responsible for *sending* such drugs harmlessly through the body may be less efficient in one individual than another.

One project of March of Dimes researchers involves studying how certain chemical growth factors affect the formation of the palate in laboratory animals.

Some investigators believe that certain facial characteristics among patients and relatives may help predict the defect. Others continue to explore ways of improving corrective measures and psychological adjustment in children already affected.

For additional copies contact your local March of Dimes chapter.

This information sheet is made possible through contributions to the March of Dimes.

March of Dimes
BIRTH DEFECTS FOUNDATION
1275 Mamaroneck Avenue
White Plains, New York 10605

Genetic Series

Public Health Education Information Sheet

SPINA BIFIDA

Spina bifida is a birth defect of the backbone (spinal column), often called "open spine." Some 1,500 babies (one in 2,000) are born with this condition each year in the United States. It is more frequent in Ireland and Wales, and less common in Israel and among Jewish people in general.

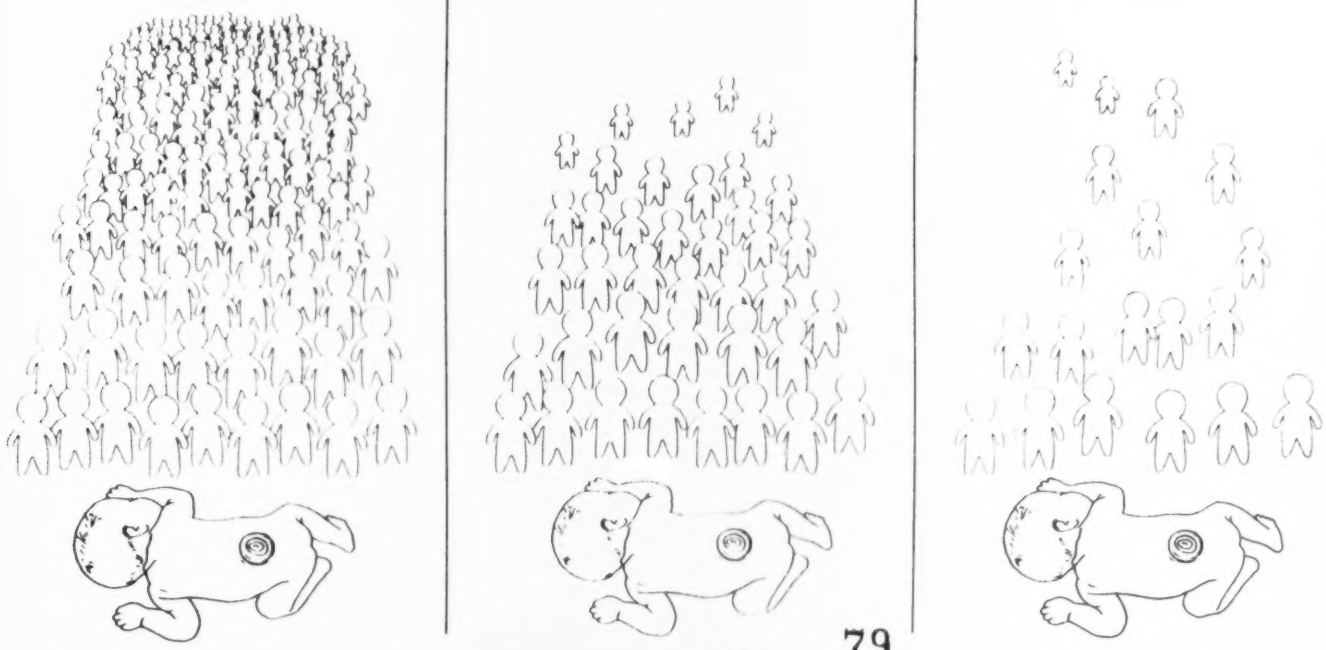
How does spina bifida affect a child?

Every unborn infant's spine is open when it first forms, but normally it closes early in a mother's pregnancy. In spina bifida, the backbone never closes completely. There are three forms of spina bifida:

- The defect may be so slight it never bothers the child and is only discovered accidentally, through an X-ray taken later for some other condition.
- A cyst, or lump, containing part of the spinal cord pokes through the open part of the spine. The lump under the skin can be as small as a nut or as large as a grapefruit, and if it is in the lower back it may cause weakness in the legs. This lump can be removed by surgery, allowing the baby to grow normally.
- In the most severe form of spina bifida, the cyst holds deeper nerve roots of the spinal cord. This lump has little or no skin protecting it. Spinal fluid may leak out, and the area often is covered with sores. Infection is a danger until surgery and healing takes place. Since this severe type is usually at the lower end of the spine, the baby's legs are paralyzed and have no feeling. Poor bladder and bowel control later become a problem.

CHANCES OF HAVING A BABY WITH SPINA BIFIDA

ALL MOTHERS	MOTHERS WITH 1 CHILD AFFECTED	MOTHERS WITH 2 SPINA BIFIDA CHILDREN
1-2,000	1-40	1-20



Hydrocephalus

Hydrocephalus, water on the brain, occurs in 70 to 90 percent of children with severe open spine. This happens when spinal fluid collects in and around the brain, causing the head to become enlarged. If the fluid isn't drained away regularly, mental retardation may result. Hydrocephalus may also occur without spina bifida.

Can spina bifida be treated?

When the spinal defect is so slight that it is hardly noticed, no treatment is needed. If there is a lump but no leg paralysis or loss of feeling, doctors can operate to prevent damage.

When a baby is born with the most severe form of spina bifida, it usually is operated on at once — within 48 hours after birth. Doctors remove the large, runny cyst and cover the wound with muscle and skin. Even so, the leg paralysis and lack of feeling can't be cured.

As soon after the operation as possible, a physical therapist teaches the parents how to exercise their baby's legs and feet to prepare it for walking with leg braces and crutches. Some children may need to use a wheel chair.

If the child develops hydrocephalus, fluid can be drained from its brain through a special tube. The tube runs under the skin, down into the chest, and the fluid passes harmlessly through the child's body.

With treatment, spina bifida patients usually can become active, productive individuals. Most are able to have children, although such a pregnancy is considered "high risk."

What causes spina bifida?

The cause of spina bifida is not presently known. Scientists believe that heredity and some kind of adverse prenatal environment act together to cause this and related central nervous system (brain and spine) defects.

Although spina bifida appears to run in certain families, it doesn't follow any particular law of inheritance. If parents have one spina bifida child, the risk of having a second is about one in 40. If there are two affected children in one family, the risk of having a third is about five percent. There also is a two-fold increase in the chance of having these defects among cousins of the spina bifida baby.

Within each ethnic group where the defect is most common, it occurs about three or four times more often among poor people than among the wealthy.

Can spina bifida be prevented?

At present there is no method to prevent the defect or treat the affected baby before birth. Genetic counseling can help parents of spina bifida children and their relatives by letting them know the odds for having other babies with the defect. Counselors can explain the defect to expectant parents and prepare them for the medical care their child may need. Genetic counselors also will know where the nearest spina bifida clinics or parent organizations are located.

What is the research outlook?

Scientists constantly seek answers to the cause, prevention, and treatment of spina bifida, hydrocephalus, and related defects. Researchers funded by the March of Dimes have been studying the effects of drugs and chemicals of the body on central nervous system development. They are studying how viruses, drugs, growth-promoters and other agents in the earliest stages of a baby's development may influence the way the nervous system grows.

Other investigators are looking for ways to drain fluid from the brain without surgery. They also are studying biochemical changes in parts of the brain affected by hydrocephalus, with the hope of preventing possible brain damage.

For additional copies contact your local March of Dimes chapter.

March of Dimes
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1275 Mamaroneck Avenue
White Plains, New York 10605

Public Health Education Information Sheet

RUBELLA

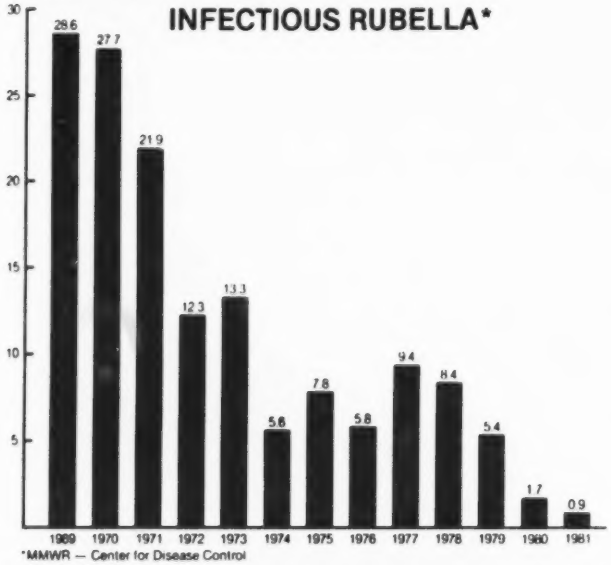
More than 20,000 babies were born with birth defects during an outbreak of rubella (German measles) in 1964-65. Their mothers caught the disease while pregnant, and passed it on to their developing babies. At least 10,000 unborn and newborn babies died of rubella during that same epidemic. Before vaccination against rubella became possible in 1969, smaller outbreaks happened every five to nine years. This cycle of the big outbreaks has been stopped, but rubella still kills or cripples babies before and after birth.

The March of Dimes hopes to wipe out rubella by educating people about the disease and the need to vaccinate against it.

What Is Rubella?

Rubella, sometimes also called three-day measles, is a mild, infectious (catching) disease caused by a virus. Rubella is not the same as regular measles, which is called rubeola. The two different diseases only sound alike — and both cause skin rashes (redness and itching).

Rubella used to seem so harmless that nobody paid much attention to it until 1941, when doctors began to realize that babies whose mothers caught it early in pregnancy often had birth defects. Although rubella is thought of as a childhood disease, many adults and teenagers get it too.



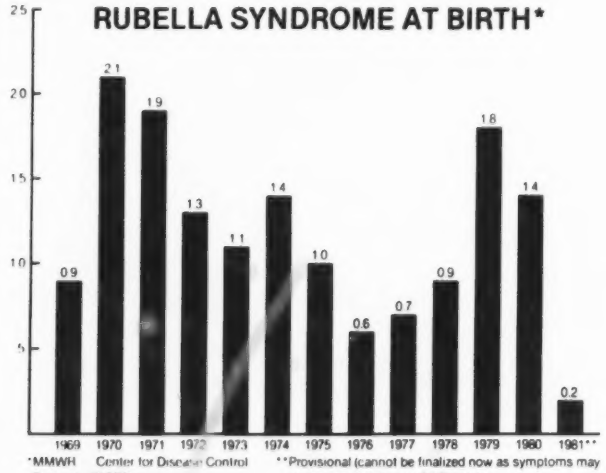
How Does Rubella Affect A Person?

A rash is the first noticeable symptom, but rubella really starts two to three weeks before the rash shows up. This "ripening" time is called the incubation period. A few days before the rash appears, the infected person may have painful lumps behind the ears, in the neck, and around the lower back of the head. The tenderness goes away in a day or two, but the swelling lasts longer.

The rash may start on the face and quickly spread down the body, arms, and legs. It usually lasts about three days. It may go away before that, and sometimes there may be no rash at all. A little fever usually goes along with the rash. Other symptoms, such as headache, loss of appetite, sore throat, and a general sick feeling are more common in adults and teenagers than in children. Aftereffects of rubella are rare among children, although there have been cases of joint pains, sleeping sickness, and blood clotting problems. Adults, especially women, often are left with joint pains.

How Does Rubella Affect An Unborn Baby?

The biggest problem with rubella is the damage it can cause an unborn baby whose mother catches it during pregnancy. The first three months are the most dangerous, but the fetus can still be affected by rubella after that time. The earlier in pregnancy that the mother has rubella, the more serious the birth defects usually are. Some "rubella babies" die before or shortly after birth.



More common are the lifetime defects that a baby may be left with. Among these are hearing loss or deafness; eye defects or blindness; heart defects; and brain and nerve defects, such as mental retardation, slowness in learning to walk and do simple things, and behavior problems.

Some babies may have defects that aren't lasting. They may be born too small, or have feeding problems, diarrhea, pneumonia, or anemia (poor blood). Purplish spots may show up on their faces and bodies due to a bleeding tendency. Organs such as the liver and spleen may be irritated; and there may be temporary brain and spine problems.

Close follow-up of babies affected by rubella is important because some defects don't show up until later in childhood. Even if the baby seems normal at birth, treatment through surgery and training programs often is successful in correcting rubella-related defects.

Is There A Test For Rubella?

There is a simple blood test to find out if a person has rubella or has had it at some time in his or her life. People who have had rubella may have rubella antibodies (virus fighters) in their blood. If a blood test shows rubella antibodies are present, then the person has had the disease and can't get it again. The test is important for women of childbearing age even if they think they have had rubella. They may be mistaken, since many infections may look like rubella but really are not.

Can Rubella Be Prevented?

Yes. Vaccination against rubella makes people immune to the disease almost as if they had once caught it. The vaccine causes the body to manufacture rubella antibodies. Rubella vaccination has nothing to do with vaccination against regular measles. *Vaccination against regular measles (rubeola) will not protect against German measles (rubella).*

Since rubella vaccination became possible in 1969, millions of people have received the vaccine. Millions more must be vaccinated each year in order to wipe out the disease for all time.

Who Should Be Vaccinated?

Rubella vaccine is recommended for all children, most teenagers, and many adults (especially women), unless there is a medical reason why they shouldn't have it. If boys and girls are vaccinated, it keeps them from getting rubella and spreading it to others, especially to pregnant women.

Vaccinating girls as soon as they reach childbearing age (after puberty) protects their future babies. Vaccination of teenage or adult groups in colleges, work places, or military bases helps prevent outbreaks in those areas.

People working in newborn nurseries should be vaccinated, since infants born with rubella can spread it to the people around them for a while after birth.

When Should A Person Be Vaccinated?

The earliest a child should be vaccinated is 12 months of age. Before that, the baby still has some of its mother's antibodies, which can interfere with the vaccine and keep it from working.

Pregnant women *must not* receive the rubella vaccine. Women of childbearing age should be vaccinated only if they're sure thay aren't pregnant and don't expect to be for the next three months. It is a good idea for women to be tested before pregnancy to see if they have antibodies.

Persons with a fever should not be vaccinated until they are well. But a slight cold, without fever, won't make any difference. Mothers who are breast feeding may safely be vaccinated against rubella.

Some rubella vaccine formulas contain traces of chemicals that may bother allergic patients, but health professionals can check labels and choose a suitable vaccine.

If a person already has been exposed to rubella, getting the vaccine won't prevent illness, as far as we know. However, there's no reason not to vaccinate children who have been around someone with the disease. Also, there's no harm in vaccinating persons who already have had rubella and didn't know it.

Can Rubella Be Eliminated?

Scientists are constantly working to improve the rubella vaccines, while public health educators try to impress everyone — health professionals, legislators, and individuals — with the importance of keeping up with rubella testing and vaccination as each new unprotected generation comes along. Several states require rubella antibody testing of women before marriage, if they are of childbearing age. Pamphlets in marriage license offices remind applicants to be tested or vaccinated.

With these efforts, and with the encouraging results so far, the March of Dimes continues to work for the day when rubella will be eliminated as a cause of birth defects.

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March of Dimes
BIRTH DEFECTS FOUNDATION

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1275 Mamaroneck Avenue
White Plains, New York 10605

Public Health Education Information Sheet

LOW BIRTHWEIGHT

Until recent years, many doctors restricted a woman's diet during pregnancy. They believed that little weight gain and a small baby were best for safe, easy delivery. Others felt that this was not best for healthy births. Indeed a recent study showed that a 24- to 30-pound weight gain for mother and a 7-pound, 4-ounce birthweight for baby were far healthier and safer for both.

Low birthweight now is considered the most common problem at birth, affecting one in every 12 babies born each year in the United States. It helps account for some 70 percent of our infant deaths.

WHAT IS LOW BIRTHWEIGHT?

Babies weighing 2,500 grams (5 pounds, 8 ounces) or less at birth are considered "low birthweight." If they weigh 1,500 grams (3 pounds, 5 ounces) or less, they are designated "very low birthweight."

Low birthweight can be separated into two categories:

- **Preterm births** are babies born before 37 full weeks of pregnancy. These babies usually weigh less than 2,500 grams, and they account for most cases of low birthweight. The earlier a baby is born, the less it is likely to weigh, and that puts the baby at risk for many complications.
- **Small-for-date** babies (also called "small for gestational age" or "growth-retarded") may be full-term but are too small. Their low birthweight results from a slow-down or temporary halt during the baby's growth in the womb, and puts them at risks similar to those of a preterm baby.

WHAT CAUSES LOW BIRTHWEIGHT?

There are several known reasons why babies may be born too small, too soon, or both. Some are as yet unknown; others are suspected.

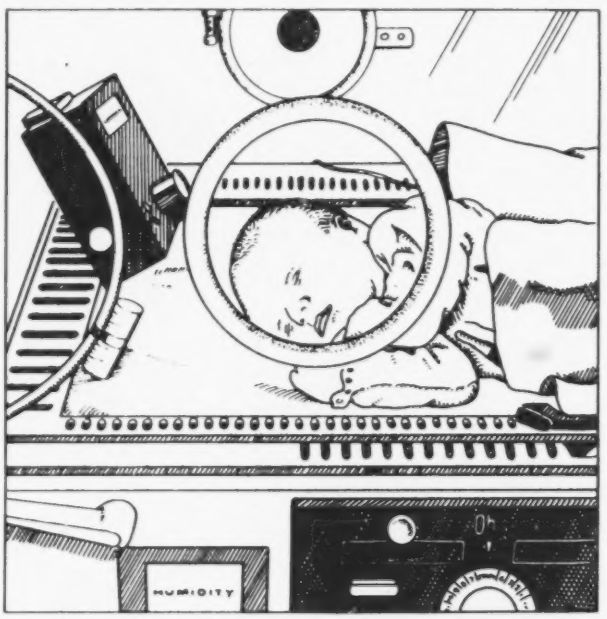
Earlier pregnancies that ended in miscarriage or a low-birthweight baby may be the result of conditions that could lead again to a low-birthweight baby. There may be an inherited disease in her family that can cause fetal defects. Defects in an unborn baby, inherited or caused by an environmental factor, may keep it from growing to its normal birthweight.

Medical background of a mother influences birthweight, especially if she has high blood pressure, diabetes, heart, kidney, or breathing problems, hepatitis, viral or bacterial infections. Toxemia of pregnancy also may cause prematurity.

A mother's habits during pregnancy may affect birthweight. Among these are:

- Poor nutrition. An unborn baby is nourished by what it's mother eats.
- Lack of early and regular prenatal care.
- Smoking, alcohol and drugs. Smokers tend to have smaller babies. Drug or alcohol use may stunt an unborn baby's growth.

Social factors, such as low income or little schooling, may place mothers at risk of having a low-birthweight baby. These mothers may be unable to afford good food and health care, or have never learned how to take care of themselves. Teenagers, especially, may not know or care about improving their health habits. Teenagers under 17 are among the mothers at greatest risk of having low-birthweight babies.



HOW ARE LOW BIRTHWEIGHT PROBLEMS TREATED?

Special life saving equipment in intensive care nurseries helps to sustain small babies who otherwise might not survive. If a baby has trouble breathing, special cribs (isolettes), oxygen, and medication are right at hand. If the baby has low blood sugar, glucose can be fed through its veins.

If the infant is jaundiced, it may be treated with special lights in the nursery (phototherapy). If anemic, it may be treated with dietary iron supplements. In severe cases, it is given a blood transfusion.

Bleeding in the brain can't be corrected except in rare

cases where vitamin K may help. Doctors watch for and treat the secondary effects of brain bleeding to help prevent possible brain damage. They examine normal spaces in the brain (ventricles) with such devices as ultrasound or CAT scanners. The spaces may begin to fill with fluid, which could be damaging. Doctors may put a tube inside to help drain the fluid off (shunting). In other cases, a hollow needle is put into the lower spine to drain off fluid. This is done every few days or so, until, as often happens, the excess fluid build up stops.

HOW DOES LOW BIRTHWEIGHT AFFECT A BABY?

Any of the complications that can happen to a newborn are more likely to happen to a low-birthweight baby than one of normal size.

The baby may have trouble breathing. Its lungs may not get enough oxygen to supply its blood system and body tissues. Some low-birthweight babies have low blood sugar (hypoglycemia), which may cause tremors, eye-rolling, poor appetite or brain damage. Jaundice (yellowish skin) may show that the baby's liver is slow to start working on its own. (During pregnancy, the mother's liver works for both of them.)

A premature baby may be anemic (have fewer red blood cells). Normally, the unborn baby stores iron during the later months of pregnancy and uses it in early infancy to make red blood cells. Born too soon, the infant may not have enough time to build up iron stores.

Low-birthweight babies may not have enough fat under their skins to help keep a healthy body temperature. This can cause blood chemistry changes and slow growth.

One of the most severe results of low birthweight is bleeding in the brain. It happens to 40 to 45 percent of infants weighing less than 1,500 grams and may result in brain damage or death.

Later in childhood, nervous system and behavior problems may occur, as a result of the low birthweight.

CAN LOW BIRTHWEIGHT BE PREVENTED?

Through public and professional health education, parents and health care workers can learn how to avoid or treat many factors that may contribute to low birthweight.

The first step is **early and regular prenatal care.** Health care professionals often can tell in advance which pregnant women or unborn babies may be at risk. Threatening medical conditions often can be safely treated and good health habits outlined. Weight gain can be carefully watched for unusual changes that might affect birthweight.

Among programs sponsored by the March of Dimes, a recent San Francisco study showed that preterm delivery (birth before 37 weeks) could be prevented in a large number of cases when the start of preterm labor was noted early enough for drug treatment to be effective.

Through public health education and community programs, **good nutrition** can be taught and made available where needed, mothers can be motivated to take care of their health, and to avoid cigarette smoking, alcohol use, and taking unprescribed drugs.

WHAT RESEARCH IS BEING DONE ON LOW BIRTHWEIGHT?

The March of Dimes supports many areas of research related to the cause, prevention and treatment of low birthweight. Investigators are studying fetal cells and the role of hormones in promoting fetal growth. They also are studying hormone influence on newborn blood sugar put out by the liver, to help prevent damaging low blood sugar levels.

Scientists are looking for the causes of bleeding in the premature baby's brain, to learn why some have it and others not.

Researchers are seeking a better understanding of how labor starts, to help find ways of preventing preterm labor. They are looking for better ways of treating breathing difficulties, to prevent side effect damage to the lungs and eyes. Temperature regulation in newborns is under research, and so are environmental factors in the nursery (light, noise, etc.) that might disturb growth.

Other grants support study of home care of low-birthweight babies for ways to prevent possible later mental and behavior problems.

For additional copies contact your local March of Dimes chapter.

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White Plains, New York 10605

Genetic Series

Public Health Education Information Sheet

DOWN SYNDROME

What Is Down Syndrome?

Down syndrome is a combination of birth defects including mental retardation. Formerly, it was called mongolism because most infants with this birth defect have a somewhat Oriental appearance. "Mental retardation" means that the child does not learn as quickly as other children, due to abnormal brain formation.

What Does A Child With Down Syndrome Look Like?

The child may have oval-shaped eyes, a tongue that seems big for the mouth, a short neck. The head may be flattened in the back and the ears small and sometimes folded a little at the tops. The nose is also flattened and wide. The child or adult with Down syndrome is often short in stature and has unusual looseness of the joints.

How Serious Is The Mental Retardation

The degree of mental retardation varies widely, from mild to moderate to severe. Most fall within the moderate range, but all are retarded to some degree. There is no way to predict the mental development of a child with Down syndrome from the physical appearance.

What Can A Child With Down Syndrome Do?

A child with this birth defect can usually do most things that any young child can do, such as walking, talking, dressing and being toilet-trained. However, they do these things later than other children. As with other children, you never can know exactly at what age these developmental milestones will be achieved.

Can A Child With Down Syndrome Go To School?

Yes. There are special programs beginning in the preschool years to help each child develop skills as fully as possible. These programs continue through the school years and there are special work programs designed for adults with Down syndrome. The extent of achievement is determined by the development of the brain and the social environment in which the child lives.

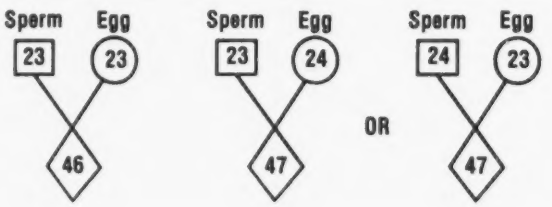
Do Children With Down Syndrome Have Special Health Problems?

Many have heart abnormalities and frequently, surgery can correct these problems. A child with Down syndrome may have many colds, bronchitis and pneumonia. These children, like all others, should receive regular medical care including eye and hearing tests as well as regular immunizations.

Many adults with Down syndrome age faster than their normal age group. Life expectancy among Down syndrome adults is about 50 years of age, but this varies widely.

What Causes Down Syndrome?

A baby is formed when the egg from the mother and the sperm from the father come together. Normally, egg and sperm cells each have 23 chromosomes. Chromosomes are the hereditary information "packets" of every living cell. In the usual case of a child with Down syndrome, either the egg or the sperm cell contributes 24 chromosomes, instead of 23. The result is that the chromosomes present total 47, instead of the normal 46. The extra chromosome causes the mental and physical characteristics of Down syndrome. This cause of Down syndrome is called trisomy 21, because of the presence of three #21 chromosomes. Certain other accidents involving chromosome #21 in egg, sperm or very early embryo also cause Down syndrome, but account for less than 5 percent of cases.



Can A Down Syndrome Baby Be Cured?

There is unfortunately no cure for a child born with this birth defect. Although many claims are made, science has yet to develop the means to prevent the cause of Down syndrome.

Can Down Syndrome Children Marry?

Some young people with Down syndrome have married, but this is unusual. A man with Down syndrome has never fathered a child. A woman with Down syndrome has a 50-50 chance of having a child with the same condition. Many people with Down syndrome require someone to care for them.

Is There Something Wrong With Parents Of A Down Syndrome Child?

Usually not. The phenomenon which causes the extra chromosome can happen in any egg or sperm cell. The extra chromosome can come from either parent. In rare cases it occurs in an embryo formed from a normal egg and sperm, or results from a chromosome rearrangement throughout a healthy parent's cells.

Who Has The Greatest Chance Of Having A Down Syndrome Child?

Parents who have already had a baby with Down syndrome, a mother or father who has a chromosome rearrangement as mentioned above, a mother who is over 35 years old. The chances of an older woman having a baby with Down syndrome are the same whether it is the mother's first pregnancy or not. Down syndrome is the most common genetic birth defect. It affects all races and economic levels of society equally.

Can Down Syndrome Be Diagnosed Before The Child Is Born?

Yes. If there is reason to be concerned about the possibility, a test called amniocentesis can be done in the fourth month of pregnancy. Any family who has a mentally retarded child or a child with other birth defects can discuss the test with a doctor or other health professional who may refer them to a genetic counseling center. The test cannot guarantee the birth of a normal child, but it can indicate whether Down syndrome is present in the fetus.

What Is The March Of Dimes Doing To Prevent And Treat Down Syndrome?

Funding scientific research is the principle means by which March of Dimes is seeking to prevent Down syndrome. Much effort is directed to investigation of the complex structure of chromosomes, and the genes which are contained in all chromosomes, including #21. Other research projects deal with the amelioration of Down syndrome.

For additional copies contact your local March of Dimes chapter.

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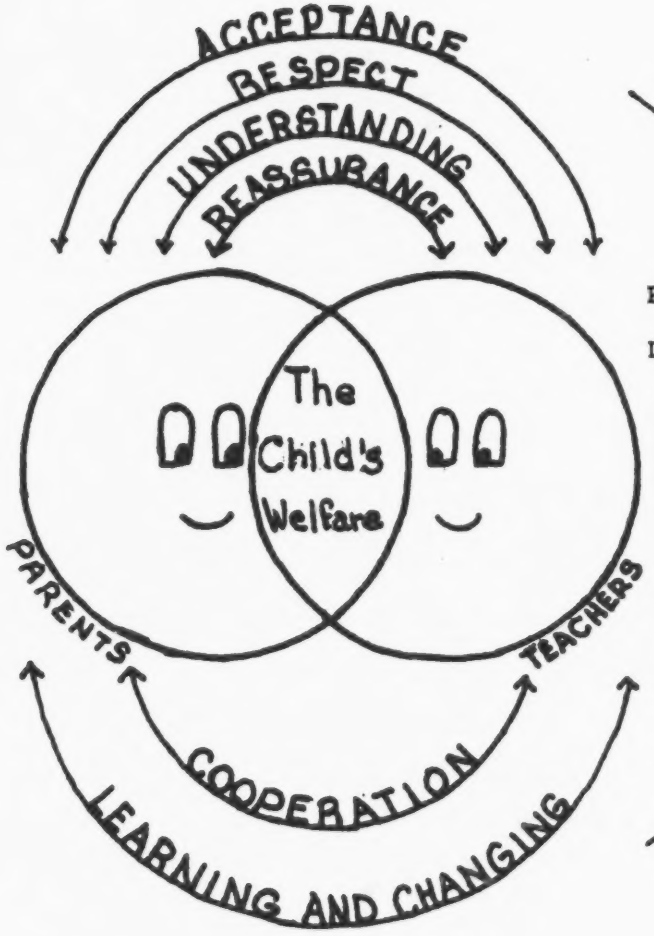
" WHAT CAN PARENTS DO? "

PARTNERS IN MEET_NG THE NEEDS OF THE CHILD

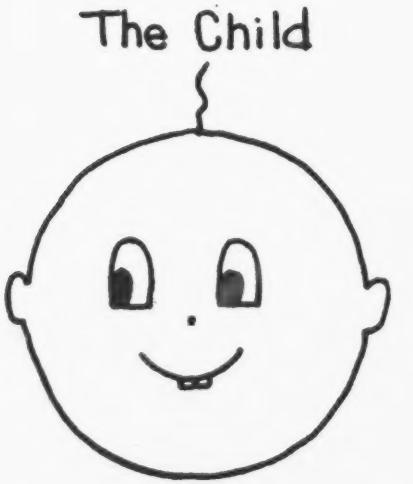


FOCUS ON THE CHILD

PARENT INTERVIEW

DOCUMENTED CONTACTS

- conferences
- home visits
- parent visits to classroom
- phone calls
- newsletters
- group meetings
- open house



PARENTS AND TEACHERS GROW

IN AWARENESS OF

CHILD'S STRENGTHS AND NEEDS

- Samples of Child's Work
- Accounts of Child's Behavior

Information from the National Information Center for Handicapped Children and Youth

March, 1984

You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap

By Patty McGill Smith

IF YOU HAVE RECENTLY LEARNED that your child is developmentally delayed or has a handicapping condition, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a handicap, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of *denial*—"this cannot be happening to me, to my child, to our family." Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by feelings of *grief* and inexplicable *loss* that one does not know how to explain, nor how to deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?". Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?".

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of handicapped persons one has known. Sometimes there is guilt over some slight committed years before toward a handicapped person. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt*—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?". For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertantly let her

drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the handicap.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?", or "Why my child?", many parents are also saying, "Why has God done this to me?". How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?". One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a handicap is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a retarded boy.

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Handicapped Children and Youth has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to the National Information Center to get that local information.

Talk with Your Mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request *accurate* information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions be-

fore entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is *your* child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Bitterness and Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to be handicapped, one of the other things pointed out to me was that she was (and still is) a very healthy child. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have raised.

Keep in Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are somethings that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then to set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of our country, assistance is available to help you with whatever problems you are having. At the end of this paper, a person is listed who will help you get started in gaining the information and assistance you need. While finding programs for your handicapped child, keep in mind that programs are also available for the rest of your family, too.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel *with* another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say, or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This Is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

Patty McGill Smith has recently moved to Washington from Omaha, Nebraska with her two youngest daughters, Marianne, age 17 and Jane, age 13. Jane, who was diagnosed at 14 months of age, has a mental handicap and epilepsy. She has been the source of inspiration for her mother's writing and her second career.

Patty's first career was at home raising seven children. The five older children are currently in five other cities of the mid-west. They are involved in careers in law, mental retardation, biology and two are in their first year of college.

The second career for Patty began as the staff coordinator of the Pilot Parents Program of the Greater Omaha Association of Retarded Citizens. This eventually became a four state center for Pilot Parents and a national resource for information about parent to parent programs.

In 1979 Patty moved to the Meyers Children's Rehabilitation Institute at the University of Nebraska Medical Center where she coordinated statewide services for parents, siblings, advocates, and professionals working with parents.

On January 16, 1984, she became Deputy Director of the National Information Center for Handicapped Children and Youth. Patty views this as a "wonderful opportunity" for a parent to serve as the link and liaison to parent organizations and groups nationwide. One of her major responsibilities will be to facilitate the exchange of as much current information and support among parents as possible. She invites parents everywhere to send information about the programs and the good things that are happening in helping parents where they live. Parents in need of assistance may write to:

Patty Smith, *Deputy Project Director*
National Information Center for Handicapped Children and Youth
1555 Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209

This newsletter was developed by InterAmerica Research Associates, Inc. pursuant to contract 300-82-0247 with Special Education Programs of the U.S. Department of Education. The contents of this publication do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Government.

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National Information Center for Handicapped Children and Youth
Box 1492
Washington, D.C. 20013

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Become Part of The National Exchange Network

With this newsletter, The National Information Center for Handicapped Children and Youth continues a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to Toni Haas, Director. The National Information Center for Handicapped [illegible] 1555 North Wilson Boulevard, Suite

THE SEVEN STAGES

1. Confusion - A reality before diagnosis is made. Often professionals are unsure and require a planned time interval for study of the child. Parents are uncertain, bewildered.

2. Denial - When presented with the diagnosis, the parents do not accept it. "He'll outgrow it." "How could that doctor know? He only spent 5 minutes with my child." "Uncle Herman's third child had the same thing and he's okay now." Attention is often focused on one small item and the total picture is ignored: i.e. "He can spell 'cat' therefore, he is not retarded."

3. Anger-Guilt - An aggressive outgoing parent will turn his dismay outward, often against the doctor who first made the diagnosis. Also common is to turn against the spouse. Occasionally the obstetrician is accused, etc. The passive parent will turn his disappointment inward: "What did I do wrong?" "Did I really want this child?"

4. Hope - There may be excessive hope for a miracle. Frantic searching for a "cure." "Shopping" from doctor to doctor, medical centers, etc. without allowing for consistent treatment.

5. Depression - A resigned attitude but an unhealthy one. May range from "blue" and listless to real withdrawl and an attempt to hide the child. Indicates that the diagnosis of the child's handicap is accepted.

6. Acceptance - Fast progress is made if a correct program which cares for the total child is offered. Programs can include: medical care, educational therapy, physical therapy, speech therapy and psychological management. They should work together in a team effort. The parent will be an important "working" member of the team.

7. Understanding - The parent not only understands his own child, but is enriched by having to strengthen his own ability to cope with life. He can now help others.

A parent of a mentally or physically handicapped child may experience these seven emotions in a fairly predictable order. The amount of time spent at each stage varies widely from a few seconds to many years.

By: Mary Leydorf, M.D., F.A.A.P.
Taken from: "We've been there ...Can We Help?"
Project C.O.P.E., Montclair, California

PILOT PARENTS OF ARIZONA

A Support Network For Families Of Children With Disabilities

CENTRAL OFFICE

2005 North Central Avenue
Suite 100
Phoenix, Arizona 85004
(602) 271-4012

The PILOT PARENTS PROGRAM offers a unique type of support which cannot be provided by family, friends, clergy, or physicians.

PILOT PARENTS OF ARIZONA allows us to develop and provide this service to communities throughout Arizona.

PILOT PARENTS are experienced parents who are intimately familiar with the emotions, fears, and realities that parenting a child with special needs can present.

— *PILOT PARENTS* understand the shock, pain, aloneness, and helplessness that new parents feel - they have "been there". They have no magic answers, but volunteer their time to listen and share their own experiences.

— *PILOT PARENTS* are knowledgeable and have access to information regarding resources and services available to families and their special needs child.

— *PILOT PARENTS* have been trained to assist and guide new parents of a child with a disability.

PILOT PARENTS TRAINING

To become a pilot parent it is necessary to be a parent of a child with a disability (foster and adoptive parents welcome) and complete a training. The training sessions utilize pertinent audio-visual materials, role playing techniques, and discussions. Information covered during training includes: orientation to the program, development and philosophy, effective listening and communication skills, program referral procedures, etc.

Training to become a pilot parent is available to local communities throughout the state of Arizona, upon request.

REFERRAL PROCEDURES & SERVICES:

Referrals of new families to the Pilot Parents Program are received from physicians, hospital nurses or social workers, public and private personnel, parents, and friends.

A Pilot Parent Coordinator matches the new family with an appropriate pilot parent, taking family similarities and geographic location into consideration. If a match cannot be made within the local community, attempts will be made to match the new parents with a pilot parent within the state of Arizona.

The pilot parent will contact the new family by telephone as soon as possible. Depending upon geographic location, a hospital or home visit may be scheduled. During the initial visit, the pilot parent will provide the family with a "New Parents Information Kit" containing literature on the child's specific disability and information on local, state, and national support groups. This kit may be mailed if necessary or preferred.

PILOT PARENTS OF ARIZONA will accept referrals from professionals and friends if the family has authorized them to initiate the contact. If preferred, parents may contact the program themselves.

If you know of someone who could benefit from talking with a Pilot Parent, or if you would like more information about our program, please contact us.

DISABILITIES SERVED STATEWIDE INCLUDE BUT ARE NOT LIMITED TO:

- *Arthrogryposis*
- *Autism*
- *Cerebral Palsy*
- *Chronic Illness*
- *Cleft Lip & Palate*
- *Congenital Heart Defects*
- *Cystic Fibrosis*
- *Developmentally Delayed*
- *Down Syndrome*
- *Dwarfism*
- *Epilepsy*
- *Fetal Alcohol Syndrome*
- *Genetic Disorders*
- *Hearing Impaired*
- *Hydrocephalus*
- *Juvenile Rheumatoid Arthritis*
- *Microcephaly*
- *Multiply Handicapped*
- *Near Drowning*
- *Mental Retardation*
- *Muscular Dystrophy*
- *Orthopedically Handicapped*
- *Spina Bifida*
- *Visually Impaired*

No fees are charged

THROUGH THE PILOT PARENTS PROGRAM EXPERIENCED PARENTS OF CHILDREN WITH DISABILITIES PROVIDE PEER SUPPORT AND PRACTICAL INFORMATION TO FAMILIES WANTING ASSISTANCE.

THE NAME "PILOT PARENTS" COMES FROM THE OLD RIVERBOAT PILOTS IN ROUGH WATER. PEOPLE WHO HAVE NEVER BEEN THROUGH THE WATERS NEED SOMEONE WHO "KNOWS THE WAY".

"From my exposure to the Pilot Parents Program, I have consistently found it to be a most innovative and effective aid to parents of handicapped children."

Frank J. Menolascino, M.D.
Past President of the
National Association for
Retarded Citizens

"The Pilot Parent Program is by far one of the best run and most effective operations of its kind in the Nation."

Robert Perske
President's Committee on
Mental Retardation

Pilot Parents of Arizona is funded by the Arizona Department of Economic Security, Division of Developmental Disabilities. The Pilot Parents Program has been operating in Arizona since January, 1979.

We have pilot parents and parent contacts in the following communities:

Casa Grande
Cottonwood
Flagstaff
Holbrook
Lakeside
Phoenix Area
St. Michaels
Sierra Vista
Whiteriver
Claypool
Havasu
Kingman
Nogales
Prescott
Show Low
Tucson
Yuma

IF YOUR AREA IS NOT LISTED, PLEASE CONTACT:

Nancy P. Morgan
Statewide Coordinator
CENTRAL OFFICE

FOR MORE INFORMATION ON THE PILOT PARENTS PROGRAM IN YOUR AREA, CONTACT:

Judy White
White Mountain Apache
Head Start
Box 738
Whiteriver, AZ 85941
(602) 338-4938

PARENTS CAN:

Be positive--praise your child's efforts and accomplishments no matter how small they may seem

Encourage independence--allow exploration, assign simple reasonable chores such as hanging up clothes (on reachable pages), caring for toys, etc.

Be consistant in your demands

Talk to your child--name objects and clothing, describe your activities and the child's activities, discuss TV shows, read stories and discuss illustrations

Listen to your child--clarify or enlarge on his statements using correct form and words without admonishing him or neglecting the content of what he says

Auditory Activities

Call attention to sounds and sound differences such as loud/soft, same/different, etc.

Question him about what he hears or what is there to be heard--local animal or traffic noises, other people in the house, etc.

Sing songs and say rhymes emphasizing sounds and rhythm

Language Activities

Provide activities for your child to talk about--walks in the neighborhood, special activities at home, shopping trips, etc.

Read to your child

Talk to your child--not a barrage of words, but describing what you're doing, what he's doing, what comes next, etc.

Listen when your child talks and ask appropriate questions to show interest and expand ideas

Play simple games like Simon Says, Ring Around Rosie, London Bridge, etc.

Visual Activities (motor activities have some relevance)

Discuss objects and their placement--in, on, near, etc.--their shape and color

Discuss illustrations in books--look for specific actions or objects

Encourage observations on short walks or trips

Question your child about what he sees or what there is to be seen and what things look like--color, shape, location, action, etc.

PARENTS CAN: (Con't)

Motor Activities

Allow your child to explore your house, yard, and neighborhood with proper supervision--most falls or mishaps are minor

Play games like Ring Around Rosie, London Bridge, Simon Says, Blind Man's Buff

Provide experience with crayons/pencils

Provide experience with blunt tip scissors such as in cutting up old magazines

Snap type clothes pins make good toys while building strength and coordination

Provide experience in stacking--with pots and pans, measuring cups--matching appropriate lids to pots and pans or screwing lids on empty plastic bottles of various sizes (Also good for developing visual judgment)

Cognitive Activities

Discuss sequence of routines--what comes next? What happened before? etc.

Use simple chores to teach matching/sorting--pairing socks, putting appropriate lids on pots, putting toys away according to color or shape

One-to-One relationships as in counting in setting the table--one utensil for each person to use

"WHAT CAN TEACHERS DO?"

TEACHERS CAN:

Teach almost anything with almost anything. Remember to just ask the right questions in using the material.

Language Skills

Encourage the child to talk--show pictures to be discussed or a story to be made about them, take field trips, question about activities at home (not prying of course), ask questions that require more than "yes" or "no"

Listen to what the child says!

Repeat correctly words or phrases or sentences the child uses--be sure you use a tone and manner that does not make the child feel he's made a mistake, rather make it seem that you are repeating what he said to be sure you have the right idea.

Expand on what the child says--If he mentions the big truck, add something about the big blue truck, or the big blue truck in the corner

Talk about what you are doing--watch your own language, be sure you use complete sentences, that you speak slowly and clearly in the language the child understands.

Ask if the child understands you

Read to the child

Say nursery rhymes omitting key words or repeated phrases to be supplied by the child

Provide toy phones, puppets, tape recorders, etc.

Schedule "Show and Tell" sessions--keep the group to a size comfortable for the child

Auditory Skills

Give clear, simple, correctly sequenced directions accompanied by modeling or example; give only as many directions as the child can use at one time

Call attention to and discuss sounds that are there to be heard--schedule special quiet listening times

Play records of familiar sounds

Play sound localization games--Have a child hide and give clues by making a small noise

Play direction--following games like Simon Says or have the child repeat words or phrases after you

TEACHER'S CAN: (con't:)

Auditory Skills (Con't)

Teach songs and rhymes

Practice verbal absurdities--Do ponies shave?

Ask questions as you read a story to the children

Pose easy riddles--What has four wheels and a windshield and a driver?

Visual Skills

Provide sorting/matching tasks--with blocks, toys, pictures, etc. according to color, shape, use, texture

Encourage such activities as driving toy cars along toy roads

Play target games with beanbags or balls

Show pictures and suggest--find specific objects or actions, or hidden objects or missing parts of an object. It may initially help to outline objects or to use a frame to help the child focus on just part of a picture at a time. You may want to begin with very plain pictures, gradually increasing the amount of detail available

Provide experiences for observation--field trips, times to look out the window, etc. and discuss what the child sees or is there to be seen

Provide pegboards, formboards, beads, building blocks and puzzles (some with pieces consisting of a whole objects, others with pieces fitted together to form the object.)

Allow the child to play with a flashlight in a darkened room, drawing pictures and following the light or guessing what other children are drawing

Motor Skills--gross motor

Set up obstacle courses with balance beams or taped lines, tunnels, stairs, etc.

Play follow the leader requiring jumping, hopping, top toe, rolling, walking backward, balancing, etc.

Play dancing games like the Hokie Pokie or direction following games like Simon Says requiring movement of different body parts in different ways

General calisthenics

Put different body parts in different relationships with things or people--e.g., put your front next to someone else's front; put your side behind the chair

TEACHER'S CAN: (Con't)

Motor Skills--fine motor (Many of the visual activities are relevant here)

Play balancing or stop action games like freeze tag or status

Provide pegboards, puzzles, buttons, lacing--sewing cards, snapping beads pinch clothespin, stencils

Allow lots of cutting, pasting, coloring tracing activities, beginning with free expression and moving up to making specific things, coloring shapes and pictures and dot-to-dot pictures

Self-Help Skills

Encourage and allow time for children to help with chores around the classroom--setting up for breakfast, lunch or snack, cleaning up after themselves or taking turns cleaning up after the class from meals or activities such as painting

Cook with the class--NAEYC has an excellent book on cooking in the classroom providing appropriate easy-to-use recipes and organizational suggestions

Set up a housekeeping center to allow dress-up play, dressing of dolls, and role-playing of meal preparation and clean up as well as social interactions

Make things about the child--life-size body pictures, self-portraits, books detailing their interests, skills, and experiences

Cognitive Skills

Select materials in each of the other areas which reinforce the particular concept you have in mind and ask the right questions. For example, if you want to teach prepositional relationships, you might build language by introducing the word needed and having the child repeat it and make sentences about things that illustrate that relationship. Auditory and Visual skills might be built by making statements about that concept that requires the child to look at things in the classroom and judge if they do show that relationship or not. Motor skills might be built by asking the child to demonstrate the relationship with various parts of his body (gross motor) or with various objects (fine motor)

" WHAT RESOURCES ARE AVAILABLE "

RESOURCES:

American Speech-Language Hearing Association
10801 Rockville Pike
Rockville, Maryland 20853

(301) 897-5700

Arizona Department of Health Services
Crippled Children's Services
10th Street and Willetta
P. O. Box 2989
Phoenix, Arizona 85062

(602) 239-6980

National Association for the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

(301) 587-1788

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, New York 10016

Alexander Graham Bell Association for the Deaf
3417 Volta Place, N.W.
Washington, D.C. 20007

(202) 337-5220

American Cleft Palate Education Foundation, Inc.
331 Salk Hall
University of Pittsburg
Pittsburg, Pennsylvania 15261

(412) 681-9620

Cystic Fibrosis Foundation
Suite 309
6000 Executive Boulevard
Rockville, Maryland 20852

Little People of American Foundation
Box 126
Owatonna, Minnesota 55060

National Foundation for Ectodermal Dysplasias
108 North First, Suite 311
Mascoutah, Illinois 62258

(618) 566-2020

Dystrophic Epidermolysis Bullosa Research Assoc. of America
2936 Avenue W
Brooklyn, New York 11229

(212) 769-4568

Epilepsy Foundation of America
1828 L. Street, N.W.
Washington, D.C. 20036

American Heart Association
44 East 23rd Street
New York, New York 10010

The National Hemophilia Foundation
19 West 34th Street, Room 1204
New York, New York 10001

(212) 563-0211

Committee to Combat Huntington's Disease
250 West 57th Street
New York, New York 10019

(212) 757-0443

Hydrocephalus Know Problems, Inc.
Jim and Linda Mazzerta
Route 1, Box 210A
River Road
Jolliet, Illinois 60436

American Lupus Society
23751 Madison Street
Torrance, California 90905

Muscular Dystrophy Association
810 Seventh Avenue
New York, New York 10019

National Neurofibromatosis Foundation
340 East 80th Street, #21H
New York, New York 10021

(212) 744-4601

American Brittle Bone Society
National Headquarters
1256 Merrill Dr., Marshallton
West Chester, Pennsylvania 19380

(215) 692-6248

Spina Bifida Association of America
343 South Dearborn, Room 319
Chicago, Illinois 60604

(312) 663-1562

STATE RESOURCES

PHOENIX AREA	TELEPHONE NUMBERS
BIA Area Office 3030 N. Central, Phoenix, Arizona 85011 Rosella Lawrence, Specialist Education Coordinator	241-2320
State Special Education 1535 West Jefferson Street., Phoenix, Arizona 85007	253-3183
Arizona Center for Law in the Public Interest - Protection and Advocacy System for Persons with Developmental Disabilities Box 2783, Phoenix, Arizona 85002 Ms. Candance McCarthy-King	252-4904 or 800-352-5335
Arizona Association for Retarded Citizens (AARC) 5610 So. Central, Phoenix, Arizona 85040 Dwayne Knuth, Director	243-1787
St. Joseph's Mental Health Center 350 W. Thomas Rd., Phoenix, Arizona 85013	274-7919 or 263-5321
Arizona Congress of Parents and Teachers 2721 N. Seventh Ave., Phoenix, Arizona 85006	279-1811
Easter Seals (Navajo County) State Office 702 North 1st Street, Phoenix, Arizona 85004 Pat Caldwell, Program Director	252-6061
Gompers Rehabilitation Center 7211 N. 7th Street, Phoenix, Arizona	934-3484

Gompers provide a Medically Oriented, Outpatient program for the treatment and training of Handicapped children and adults through specialized services which include a medical consultation board, physical restoration, psychological adjustment, personal counseling, vocational evaluation and academic programs. Disabilities treated include cerebral palsy, muscular dystrophy, multiple sclerosis, polio, arthritis, stroke, accidents, brain damage, asthma, emphysema, laryngectomies, deafness, speech disorders and autism testing and evaluation.

To provide testing and evaluation of hearing disorders. Psychological diagnosis and counseling either individual or group including family units speech evaluation and diagnostic therapy and physical and perceptual/sensori-motor intergration testing.

CONSULTING SERVICES

To provide consulting services to the community (Schools, Hospitals, Nursing homes, Business and Agencies) on a daily, weekly, monthly or yearly basis. These services may include in-service training and workshops, prescriptive teaching, contingency contracting, diagnosis and remediation techniques for all exceptionalities.

HEAVEN'S VERY SPECIAL CHILD

A meeting was held quite far from earth,
"It's time again for another birth"
Said the Angels to the Lord above,
"This Special Child will need much love.

His progress may be very slow,
Accomplishments he may not show.
And he'll require extra care
From the folks he meets down there.

He may not run or laugh or play;
His thoughts may seem quite far away.
In many ways he won't adapt
And he'll be known as handicapped.

So let's be careful where he's sent.
We want his life to be content.
Please Lord find the parents who
Will do a special job for You.

They will not realize right away
The leading role they're asked to play.
But with this child sent from above
Comes stronger faith and richer love.

And soon they'll know the privilege given
In caring for their gift from Heaven.
Their precious charge so meek and mild
Is Heaven's Very Special Child."

--John & Edna Massimilla, "This Is Our Life"